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MAPS OF MARGINALIZATION: EXPLORING THE HEALTHCARE EXPERIENCES OF MEN AND WOMEN WITH FIBROMYALGIA

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by

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Abstract

This qualitative study explored the retrospective and ongoing healthcare experiences of men and women who have a diagnosis of fibromyalgia (FM), a contested, chronic, and gendered condition of unknown origin. The research question was: "How do men and women who have a diagnosis of FM experience interactions with healthcare providers?" The study, which was epistemologically rooted in the critical theories of feminist poststructuralism and intersectionality, blended constructivist grounded theory with a participatory component, an arts-based research methodology called body-map storytelling. Thirty-five participants were recruited from the Greater Toronto Area and Kitchener-Waterloo. Ten participants completed in-depth interviews while 25 participants completed body maps within a series of focus group sessions.

Through analysis of the verbal and visual data, four key findings emerged. First, participants experienced *compromised healthcare* due to structural barriers and unsupportive attitudes of healthcare providers. Second, participants' experiences of compromised healthcare were impacted by *systems of embodied differences*. Third, participants resisted the system of compromised healthcare through strategies of self-management. Finally, participants described their experiences of helpful clinical practices, as well as their suggestions for improving FM healthcare services. The study contributes crucial information for the transformation of healthcare policies, programs and clinical practices for the FM population. As a form of applied research, the study has also helped give voice to and empower a marginalized population.

Acknowledgements

During this doctoral journey, I have been immensely grateful to receive nourishment -- intellectual, emotional, and practical -- from a remarkable community of research participants, stakeholders, academics, friends, and family. First and foremost, I would like to acknowledge the research participants who brought this study to life through their enthusiasm, commitment, and resilience. When I look at participants' body maps I experience the feeling of awe, as well as hope that through collaboration we can improve healthcare for people living with fibromyalgia.

I am privileged to work with a talented, supportive, empathetic, patient, and engaged dissertation committee. Each member has provided invaluable mentorship, enriching my life and my thinking. In 2001, as an MSW student, I first met my Dissertation Advisor, Dr. Carol Stalker. Eight years later, I reconnected with Dr. Stalker and instantly knew that I wanted her to be my advisor; Dr. Stalker has always made me feel at home at the Faculty of Social Work, fostered my academic career, and inspired me with her work ethic, writing skills, and commitment to applied research. In 2009, I met my Dissertation Co-Advisor, Dr. Juanne Clarke, who immersed me in the world of Foucault for an independent study course. I am indebted to Dr. Clarke for teaching me how to think like a critical theorist and for sharing her passion for writing and art. For three years, I worked as a Research Assistant for committee member, Dr. Marshall Fine. Dr. Fine has taught me to think deeply about the nuances of qualitative research and the complexity of ethical issues in social work practice. At a 2011 CIHR Institute for Gender Health Summer Institute, I met committee member Dr. Gillian Einstein who introduced me to the methodology of body mapping. I am energized by Dr. Einstein's commitment to creatively integrating sex and gender in the field of health research, and I am honoured to have the opportunity to work as her Postdoctoral Fellow in the upcoming year.

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CHAPTER ONE – INTRODUCTION

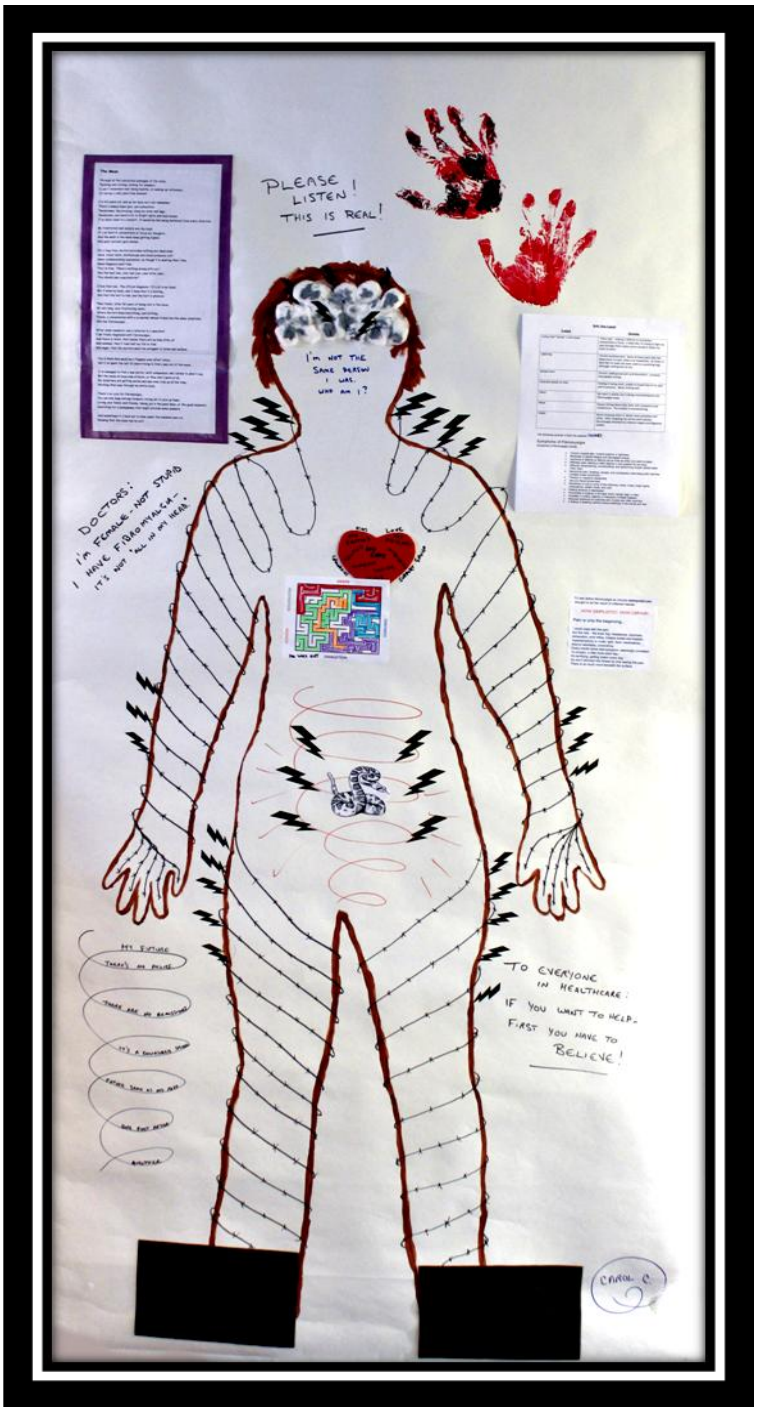


Figure 1: This study opens with the body map of a focus group participant, Lori (a pseudonym). Lori's body map highlights how healthcare experiences can be represented through the interconnection of visual and verbal forms of expression.

Lori's Poem: the Maze[1]

Through all the convoluted passages of the maze,
Twisting and turning, looking for answers.
I can't remember ever being healthy, or waking up refreshed,
Or having a calm, pain-free moment.

I'm 60 years old, and as far back as I can remember
There's always been pain, and exhaustion,
Tenderness, like bruising, along my arms and legs.
Headaches, and sensitivity to bright lights and loud noises.
I've never been to a concert. It would be like being battered from every direction.

My frustration and anxiety are sky-high.
It's so hard to concentrate or focus my thoughts.
And the walls in the maze keep getting higher,
And each corridor gets darker.

For a long time, doctors provided nothing but dead ends.
Same blood tests, stethoscope and blood pressure cuff.
Same condescending expression, as though I'm wasting their time.
Same diagnosis each time.
"You're fine. There's nothing wrong with you."
And the best one... over and over, year after year...
"You should see a psychiatrist."

I love that one. The official diagnosis: It's all in my head.
But I know my body, and I know that it's hurting,
And that the hurt is real, and the hurt is physical.

Then finally, after 30 years of being lost in the maze,
30 very long, very frustrating years,
Where doctors know everything... and nothing...
Finally, a conversation with a co-worker whose friend has the same symptoms.
She has fibromyalgia.

After some research, and a referral to a specialist,
I am finally diagnosed with fibromyalgia.
And there is relief, that maybe there will be help after all
And sadness, that it took half my life to find
And anger, that the doctors were too arrogant to listen and believe.

[1] During the process of body-map storytelling, Lori was inspired to write a poem about her healthcare experiences. Lori's poem, which is located at the top left hand corner of her body map (Figure 1), encapsulates several key study findings about the intersection of identity and healthcare experiences.

You'd think this would be a "happily ever after" story.
But I've spent the last 10 years trying to find a way out of the maze.

I've managed to find a new doctor, with compassion, who listens to what I say.
But the meds all have side effects... or they don't work at all.
My symptoms are getting worse and new ones crop up all the time,
Working their way through my entire body.

There's no cure for fibromyalgia.
You can only keep moving forward... trying not to give up hope,
Loving your family and friends, taking joy in the good days... or the good moments,
Searching for a passageway that might provide some answers.

And sometimes it's hard not to hide under the blankets and cry
Knowing that the maze has no exit.

Figure 2: Lori described her healthcare journey as:

> [A] maze with no exit and in it there is anger and there is exhaustion and loneliness and sadness and frustration, and if I could have put more negative things in there I probably would have... and there's no outlet because I unfortunately am not one of those people who gets remissions from this.

I chose to open this dissertation with research participant Lori's artwork and poetry. Lori visually and verbally expresses several themes, which emerged in this study, about the struggles of living with fibromyalgia (FM). FM is a contested condition of unknown origin. This condition is chronic and gendered, associated with high rates of comorbidities, and prevalent in children and adults in both industrialized and non-industrialized countries (Clauw, 2014).

In Canada, 1.5% of the population – 437,550 people -- have a diagnosis of FM, and 79% of those diagnosed are women (Statistics Canada, 2011) [2]. People with FM experience a constellation of symptoms including chronic widespread pain, fatigue, sleep disturbances, memory loss, and sensitivity to sensory stimuli (Clauw, 2014). These symptoms, which can unpredictably shift in frequency and severity, impact people's global functioning, quality of life, and socioeconomic status (Sim & Madden, 2008). Within Canada's FM population, for example, 21.4 % of people reported that *severe pain* prevented their ability to complete *most* activities of daily living while 23% reported that *moderate pain* prevented their ability to complete *some* activities (Statistics Canada, 2011). Furthermore, 13% of the FM population reported food insecurity, an indicator of socioeconomic marginalization, compared to 7% of the total survey population (Statistics Canada, 2011).

People with FM experience marginalization partly because the etiology of this condition remains unknown (Wolfe, 2009). Weaving back to the poem in this report's introduction, Lori described her healthcare journey as a maze with "no exit". The maze is a powerful metaphor for

[2]Statistics Canada's *The Canadian Community Health Survey (CCHS)* is the primary source of statistics about the prevalence of conditions and diseases in the Canadian population. The CCHS' target population is people over 12 years of age living in the community. The CCHS, which is administered on an annual basis, excludes FM from its core content. Although the 2014 CCHS gathered data on FM, the results have not yet been released. As such, the 2010 CCHS is the most current source of FM statistics (M. Parlor, personal communication, October 23, 2014).

envisioning the ways in which people with FM must navigate a healthcare system[3] of skepticism and diagnostic confusion. This skepticism and confusion is caused and reinforced by the lengthy and subjective diagnostic process. At this time, the existence of FM cannot be proven by biomedical tests, such as blood work and imaging. As per the Canadian criteria for FM diagnosis, doctors administer scales of widespread pain and symptom severity, thereby relying on patients' subjective perceptions and reports. Doctors must also rule out the presence of other illnesses and diseases (Fitzcharles et al., 2012). In addition, a recent Ontario study reported that patients with FM encountered doctors who not only lacked knowledge about the condition, but who were also inconsistent in their application of diagnostic procedures (Burstyn, 2013). Consequently, the process of diagnosing FM involves a maze of resources and generates considerable healthcare costs (Burstyn, 2013; White, Speechly, Harth, & Ostbye, 1999b).

FM is a condition with economic, social, and philosophical implications. Philosophically, the construction of FM has ignited a fire of questions about the legitimacy of a condition that cannot be biomedically proven (Haugli, Strand, & Finset, 2004; Wainright, Calnan, O'Neil, Winterbottom, & Watkins, 2006). This question of legitimacy has been debated by stakeholders, including patients[4], healthcare providers, researchers, policymakers and community advocates. These stakeholders possess conflicting interests, paradigms, and perspectives about the meaning of FM. Some stakeholders, who are situated within the medical model, argue that the lack of biomedical evidence disproves FM's physiological existence. For example, the author of the

[3] In this study, the healthcare system refers to a range of services provided in the publicly-funded field of mainstream/allopathic medicine and the privately-funded fields of complementary and alternative medicine (CAM). Furthermore, the field of allopathic medicine is comprised of primary (e.g. family practices), secondary (e.g. medical specialists) and tertiary (e.g. specialized hospital programs) healthcare settings.

[4] The terms patients, clients, and consumers have philosophical distinctions and are used in different healthcare contexts. This study primarily explores the experiences of people within the allopathic medical system. As such, the term patient is consistently used to reflect the terminology used within this system.

editorial “Pain is real: Fibromyalgia isn’t” argued, “The illogic of the ‘I am the evidence’ cry suggests innumeracy and an ignorance of science and logic” (Ehrlich, 2003, p. 1666).

Within the medical model, the values of “science and logic” are embedded within the dominant discourse of Cartesian dualism, whereby conditions that are invisible in the body are assumed to exist in the mind (White, Lemkau, & Clasen, 2001). This discourse has perpetuated the assumption that FM is a psychosomatic condition, a modern day form of hysteria (White et al., 2001). At the turn of the twentieth century, hysteria was associated with the repression of sexual desires, the weakness of the “second sex,” the fragility of female nerves, and the “bad influence of the uterus” (Foucault, 1965, p.138). Hysteria was viewed as “a ruse of the body,” a manifestation of the social malaise plaguing privileged, upper-middle class women (Foucault, 1965, p. 148).

Conditions such as hysteria have been considered biomedically invalid because they not only lack a proven organic etiology but are also associated with troublesome character traits and behaviors such as “emotional instability and self-dramatization” (Slavney & McHugh, 1974, p. 329). The assumption that FM is a psychosomatic condition is reinforced by the observation that many patients with FM appear physically well despite describing significant functional impairment (White et al., 2001). This discrepancy contradicts the medical model’s expectation that the severity of an illness/disease should be reflected in people’s signs and symptoms (Barker, 2002). In this light, FM is labelled as a biomedically invisible and invalid condition due to the absence of disease markers in patients’ tests and appearances.

In addition to the discourse of mind-body dualism, FM’s label of illegitimacy has been seared into public consciousness through biomedical terminology. In the medical model, FM has been defined as a syndrome, a “collection of symptoms (Barker, 2002, p .3), and most recently as

a "centralized pain state" (Clauw, 2014). The latter term refers to a "lifelong disorder beginning in adolescence or young adulthood manifested by pain experienced in different body regions at different times" (Clauw, 2014, p. 1548). Although FM is called a syndrome, a state, and a disorder, it is not considered an illness or a disease. The concepts of illness and disease both refer to an underlying etiology, and thereby implicitly bestow biomedical legitimacy (Barker, 2005; Cunningham & Jillings, 2006; Sylvain & Talbot, 2002; Webster, 2002; Wolfe, 2009). In this dissertation, I refer to FM as a condition, a middle ground between a syndrome and a disease, because this term is simultaneously ambiguous and concrete. The term condition encompasses processes of illness and disease. As such, I strategically use the term condition to convey hope that the healthcare system will eventually recognize FM as a physically-emotionally-socially complex reality. Reality can be understood as "the result of the social processes accepted as normal in a specific context" (Rosenau, 1992, p. 111).

Situation of Self

I observed the painful reality of FM while working as a coordinator in a home healthcare organization. I had several patients with FM who required homecare services, including nursing, occupational therapy, physiotherapy, and homemaking. These patients were primarily white, middle-aged, lower-class women who were socially isolated and housebound due to the severity of their symptoms. They experienced lengthy journeys for diagnosis and treatment, as well as discrimination from unsupportive attitudes of families, friends, and healthcare providers. They suffered from delegitimation, meaning that their illness experiences were "systematically disconfirmed" (Ware, 1992, p. 347). I noted similarities among these patients' experiences, questioned whether these similarities were indicative of a healthcare trend, and subsequently reviewed the qualitative literature on FM. I was intrigued to discover that some of this literature

echoed themes expressed by home healthcare patients, but I still had unanswered questions. Consequently, when I began doctoral studies I decided to develop a dissertation study on the social aspects of FM.

Although my curiosity about FM developed through the course of clinical practice, this topic also has personal significance. I could relate to the experiences of homecare patients due to my own childhood healthcare journey. At the age of nine, I began having physical pain and trouble ambulating. After months of visiting doctors, I was diagnosed with conversion disorder, a psychosomatic illness caused by the repression of feelings. Unfortunately, I was mistreated by healthcare providers who misunderstood my illness, which in turn, delayed my recovery process. As a result of my parents' determination, however, I was eventually connected to healthcare providers who were open-minded and empathetic. With the aid of this support network, I recovered by mid-adolescence. Even though this journey was lengthy and traumatic, it helped shape my identity and value system. It also solidified my conviction that healthcare providers must creatively grapple with murky areas of clinical practice. I subsequently chose to explore the murky subject of FM.

Purpose of the Dissertation Study

The 2010 Canadian Community Health Survey (CCHS) reported that 31% of Canadians diagnosed with FM --134,202 out of 437,550 people -- have unmet healthcare needs (Statistics Canada, 2011). This statistic is quite low and conflicts with the substantive findings of qualitative studies, which report that people with FM experience unmet healthcare needs due to delayed diagnosis, inefficient treatments, and discriminatory attitudes of healthcare providers (Crooks, Chouinard, & Wilton, 2008; Egeli, Crooks, Matheson, Ursa, & Marchant, 2008; Lempp, Hatch, Carville, & Choy, 2009; Sim & Madden, 2008). Given the findings of these

qualitative studies, I suspect that more than 31% of Canadians with FM experience unmet healthcare needs. I also question whether the CCHS results reflect the limitations of collecting data via telephone questionnaire. For example, perhaps participants were: uncomfortable disclosing personal information via telephone; resigned to the shortcomings of the healthcare system; or not currently receiving healthcare services due to past experiences of unmet needs. Regardless of the reason, patients' healthcare experiences, as well as their suggestions for the improvement of healthcare services, have not been fully examined. In 2012, when I proposed this dissertation study I found only one study that directly asked patients with FM how the quality of their healthcare could be improved (Egeli et al., 2008). The authors of this study argued: "Identifying patients' views of what constitute positive interactions with care professionals is essential in improving health outcomes for those who may otherwise feel disempowered by the consultation and treatment process" (Egeli et al., 2008, p. 368). This study employed a survey of open-ended questions, and therefore respondents' answers could not be probed for further understanding.

Conrad (1990) advocated that the sociology of illness should move beyond people's symptoms, roles as patients, and interactions with healthcare providers in order to include diverse meanings and experiences of everyday life. In the context of FM, however, the dearth of research about healthcare experiences highlighted that further understanding and knowledge was required. Therefore, the purpose of this dissertation study was to help fill the gap in the literature by exploring the retrospective and ongoing healthcare experiences of men and women with FM. The exploration of healthcare experiences involved the collection of data via interviews, focus groups, and body-map storytelling (Gastaldo, Magalhaes, Carrasco & Davy, 2012), an arts-based research (ABR) methodology not previously utilized in studies about FM.

Research Question

This study was guided by the primary research question: "How do men and women who have a diagnosis of FM experience interactions with healthcare providers?" In this research question, the term **e*xperience*** refers to participants' descriptions of their ongoing process of interacting with healthcare providers and negotiating the healthcare system. Experiences are nuanced, involving "subtleties and personal meanings that inhere to living with chronic illness" (Conrad, 1990, p. 1257). The term ***interaction*** captures the ways in which patients connect with providers in the context of ongoing relationships (e.g. with family physicians) and fleeting encounters (e.g. with emergency room doctors). The term ***providers*** refers to a spectrum of professionals who: are trained in a variety of healthcare-related disciplines; have direct contact with patients; and, offer services ranging from prevention to intervention, assessment to treatment.

Exploring the intersection of gender and other forms of difference.

By inquiring about the experiences of both men and women, this study's research question was structured to examine the gendered aspects of healthcare experiences. Gender and sex are overlapping concepts shaped by culture and history. These concepts "(and their relationships, contexts, and meanings) are routinely overlooked, misused, misunderstood, confused or conflated in health research" (Greaves, 2012, p. 4). While sex refers to biological differences, gender refers to the ways in which these biological differences are dressed in social roles, expectations, and identities (Johnson & Repta, 2012).

When I proposed this research study I was aware that FM was described as a gendered condition. As I engaged in the process of data collection and analysis, however, I realized that healthcare experiences were not solely mediated by gender, but also by intersecting forms of

difference. My understanding of intersecting differences has been informed by Einstein and Shildrick's (2009) interpretation of Derrida's concept of "diffe´rance". This concept "implies an overflowing and intermingling of categories in which there is no access to a fixed or singular essence, and in which meaning is constructed through a network of interdependencies" (Einstein & Shildrick, 2009, p. 295).

Although I did not change the research question, I widened the analysis in an attempt to explore the intersections of differences, including gender, age, class, race, and culture. These intersections contextually shift, shaping and reshaping people's subject positions (Dhamoon, 2011; Mehrotra, 2010). Although subject positions are socially located, they are also situated within the body. Men and women ***embody*** gender by internalizing social norms, as well as by externalizing these norms through the performance of physical appearance (Butler, 1988; Johnson & Repta, 2012). The concept of embodiment moves beyond the Cartesian dualism of the medical model, illuminating "the intertwining of mind and body, as well to express a dynamic interplay – a reciprocity – between the whole person and the external world" (Einstein & Shildrick, 2009, p. 295). In order to conceptualize the interconnected ways subjects are positioned within their bodies and societies, I developed the term ***system(s) of embodied differences***. This term encompasses the nuanced heterogeneity within and across the categories of men and women.

The Importance of this Study

There are seven reasons why this study is important to the field of healthcare, in general, and social work, in particular. First, this study is founded on the social work principles of social justice and equity. Second, this study reflects social work's commitment to examining the interconnection of micro- and macro-level issues. Third, this study focuses on the intrinsic value

not only of understanding experiences, but also of deeply exploring how the experiences of men and women with FM are shaped by systems of embodied differences. Fourth, the subject of difference has not been explored in previous research studies on FM. Fifth, the study contributes to the relatively small but slowly growing body of qualitative literature on FM, which has emerged from North America and Europe. Sixth, as a form of applied research, this study has helped give voice to and empower a marginalized population through body-map storytelling, a method that both verbally and visually expresses experiences. Finally, through a community art gallery and other knowledge translation strategies, this study will foster collaboration among academics, healthcare providers, program developers, policymakers, and other community stakeholders. The findings of this study will provide crucial information for the healthcare system, as it designs and implements services for the FM population.

An Overview of Subsequent Chapters

In this chapter, I have introduced the dissertation study by explaining: the relevance of FM within the Canadian context; the controversial debates about FM's legitimacy; and, the impetus for, purpose, and importance of this study. In chapter two, I intertwine the theoretical framing of this study with a literature review. I describe how this study is epistemologically rooted in critical theories, including social constructionism, medicalization, feminist poststructuralism and intersectionality. I synthesize the theoretical and empirical work of social scientists who have applied critical theories to the subject of contested illness. In chapter three, I continue to weave theory with literature by deconstructing the biomedical literature on FM. Since the early 1900s, biomedical constructions of FM have continually shifted; each decade, research studies have reported different yet unsubstantiated theories of causation. I posit that this biomedical uncertainty has contributed to the illegitimacy of FM, as well as to the

marginalization of people suffering from this unsuccessfully medicalized condition. I further explore the themes of illegitimacy and marginalization found in the small body of qualitative literature on patient and healthcare providers' experiences of FM.

In chapter four, I turn from the literature about the marginalized condition of FM to the topic of marginalized methodologies. Specifically, I explain the rationale for blending body-map storytelling -- a relatively new, participatory ABR method -- with constructivist grounded theory. I then describe this study's research design, including the procedures for recruitment, the implementation of body-map storytelling as a concrete method of data collection, and the multi-phased process of data analysis.

In the next four chapters, I report the key findings emerging from the verbal and visual data, which answer this study's research question. In chapter five, I report the findings about how participants experienced compromised healthcare due to structure barriers and unsupportive attitudes of healthcare providers. In chapter six, I report the findings related to how participants' experiences of compromised healthcare were impacted by systems of embodied differences. In chapter seven, I report the findings about the ways in which participants resisted the system of compromised healthcare through strategies of self-management. In chapter eight, I build upon the previous findings by reporting participants' accounts of supportive clinical practices, as well as their suggestions for both improving and creating healthcare services for the FM population. Finally, in chapter nine, I discuss the grounded theory that emerged from the data analysis, intertwine the relevant literature with the study's findings, outline the study's implications, and conclude with suggestions for future directions in the area of FM research.

CHAPTER TWO – THEORETICAL FRAMEWORK

AND LITERATURE REVIEW ABOUT THE SOCIAL CONSTRUCTION OF FM

Figure 3: Stu's body map.

This chapter opens with participant Stu's body map in order to highlight how researchers and clinicians have a tendency to conceptualize FM as a women's condition, thereby overlooking the experiences of men. In order to help fill this knowledge gap, this study aimed to understand not only the healthcare experiences of men and women with FM, but also how experiences are impacted by gender and other systems of embodied differences. However, before reporting findings about participants' *experiences, conditions, genders,* and *differences,* I have to explain the theoretical meaning underlying these concepts. My epistemological position is that people's experiences and subject positions, as well as their conditions/illnesses/diseases, are socially constructed and infused by societal norms and discourses.

In this chapter, I will explain how this study is epistemologically rooted in critical theories, including social constructionism, feminist poststructuralism, medicalization, biomedicalization, and intersectionality. I have synthesized the theoretical and empirical work of social scientists who have applied these critical theories to the subject of contested illness. I have argued that the diagnosis of FM has been constructed by doctor-patient relationships, corporatization, pharmaceutical companies, advertisements, social media, and patient advocacy movements. In addition to these social forces, I posit that the construction of FM has been shaped by gender and other systems of embodied differences.

Postmodern Conceptualizations of Conditions/Illnesses/Diseases

Western medicine is historically and culturally located. In this sense, bodies are constructed by historical events and understandings (Foucault, 1989). Similarly, the diseases, which are contained within these ever-shifting bodies, are "biocultural" (Morris, 1998). In a biocultural model, diseases can be understood as constructed by a nexus of biological, social, political, and economic factors.

> Even when caused by a toxin, by a microbe, or by the dysfunction of an organ, illness is a fluid process that changes as we change, enigmatic, insubordinate, subjective. It... alters under the influence of non-medical events from divorce to climate change. What biomedicine finds hard to recognize or to accept is that different observers... examining the same illness from their separate perspectives will observe different aspects of its truth (Morris, 1998, p. 5).

The biocultural model is unsettling. It moves away from the security of the biomedical model and from grand narratives of disease. The biocultural model does not comfort people by reducing the body to a machine, requiring occasional tune-ups (Morris, 1998). Furthermore, this model does not attribute health, illness, and disease to underlying biological causes (Bury, 2005). Instead, this postmodern model of disease has multiple realities and truths, providing uncertainty and unanswered questions.

Because constructions of illnesses and diseases are in a state of flux, their definitions "are contentious, and increasingly reflect societal decisions rather than traditional biomedical designations. What is a disease at one moment may not be in the next" (Wolfe, 2009, p. 3). The modification of disease is exemplified by homosexuality. Once pathologized, homosexuality is now considered a valid sexual orientation within many Western societies. This example highlights how the construction of disease is a selective form of social control, which "others" people who deviate from the norms of a given time period (Smith, 2002). In fact, the disability movement has argued that some disease constructions are a form of social oppression and discrimination (Bury, 2005).

Medicalization

The "slipperiness" of disease categories was illustrated in a survey of "non-diseases" conducted by the *British Medical Journal*. The journal's list of non-diseases included FM, as well as dandruff, teething, and baldness (Smith, 2002, p. 883). Although this list has an ironic tone, it conveys the point that an increasing number of "problems" are being medicalized. Medicalization is a "process by which nonmedical problems become defined and treated as medical problems, usually in terms of illness and disorders" (Conrad, 2007, p. 3). In this light, there is a "progressive medicalization of physical distress in which uncomfortable bodily states and isolated symptoms are reclassified as diseases for which medical treatment is sought" (Wolfe, 2009, p. 6).

In the context of FM, this "diagnosis medicalizes a vast constellation of common complaints that are associated with social, economic, and personal hardships that characterize the lives of many women" (Barker, 2008, p. 31). These hardships, which have been described as "life's lesions," produce illness (Finkler, 1994). This conceptualization highlights the ways in which systemic and gendered constraints make women vulnerable to the experience of conditions such as FM. In other words, "life's lesions" strain women's minds and bodies, impacting immunity and generating risk for legitimate physical suffering.

Put another way, the mind, the body, the symptoms of FM, the experience of living with chronic illness, the environmental context, and the act of diagnosing are all pieces of a puzzle. These pieces can be described as "social texts", which are social practices, bodily practices, and products of human activity (Fox, 1997). Texts are fragmentary and are "created by the densely interwoven network of experiences and interpretations we bring to it" (Morris, 1998, p. 6). Through this intertextuality, meanings are created, ascribed, distorted, and revised. The meaning

of a text resides in its frame, a gestalt. The frame makes sense of texts, privileges one interpretation over another, and distinguishes it from what it is not (Fox, 1997). In this light, a person's context -- her social location and bodily experience of illness -- interacts with the medical world, such as the physician's office, procedures, and interventions. Through the physician's act of diagnosis, symptoms of pain and fatigue take on a specific meaning: they become FM. This interpretive frame privileges a biomedical perspective of the body. The body becomes the primary entity, which is then divided from the mind and the environmental context. In this way, the symptoms of FM become medicalized as a bodily problem.

The process of medicalizing FM as a bodily problem has both positive and negative consequences for both the individual and society. For example, after exhausting diagnostic journeys, many individuals find the label of FM to be comforting and validating, a much-needed explanation for debilitating pain (Barker, 2002). This medicalized explanation unlocks the door to healthcare resources, such as specialists and treatments, as well as appeases others who are skeptical about the validity of "mysterious" symptoms. At the same time, the very diagnosis that validates can also punish individuals by labelling them with a contested condition. This condition becomes a scarlet letter calling into question an individual's moral character. These individuals may be seen as abusing and a burden on the healthcare system. What's more, healthcare providers may use this label to explain away new symptoms, and thereby potentially overlook the presence of other illnesses or diseases.

The twentieth century can be described as an era of "medical imperialism" (Conrad, 2007, p. 6). In this era, "physicians carved out a professional niche for themselves by negating lay knowledge and practices and promoting the medical management of natural human experiences, social ills, and personal problems" (Barker, 2008, p. 22). However, medicalization

is not merely something that is *done by* doctors *to* patients. In fact, it is an interaction, and at times patients seek to be medicalized while doctors resist the designation. Within this interaction, power is multi-directional, diffuse, dispersed, and constantly changing (Foucault, 1995).

The therapeutic domain.

The power of medicalization operates in complex, contradictory, and relational ways. For example, medicalization occurs within social settings. These settings can be described as a "matrix within which an idea, a concept or kind, is formed" (Hacking, 1999, p. 10). In the context of healthcare, the matrix is similar to the concept of the "therapeutic domain" (Hazemeijer & Rasker, 2002, p. 508). A therapeutic domain:

> [Is] always within the sphere of influence of a physician or another health professional... A therapeutic domain is a real and heterogeneous medical domain in which people, their thoughts and practices, and medical technology in any form coexist and communicate (Hazemeijer & Rasker, 2002 p. 508).

In the therapeutic domain, physicians and persons/patients engage in a reciprocal relationship of medicalization. For example, the person with medically unexplained symptoms visits her physician and is subsequently diagnosed with FM. Through this diagnosis, the person's biomedically invisible symptoms are given visibility, meaning, legitimacy, and embodiment (Hazemeijer & Rasker, 2002). The person then leaves her physician's office as a "fibromyalgia patient." This person's new subject position helps her to explain past suffering, elicit empathy, and access resources such as disability benefits (Smith, 2002).

The person's subject position is not only shaped by the medical environment, but is also mediated by representations of FM in popular culture. For instance, she can identify with the women in advertisements for FM medications, such as Lyrica. She internalizes these images,

which in turn, mediate her experiences and perceptions of reality (Lyons, 2000). This interplay of perceptions and messages -- generated by the physician, the person/patient, and the media -- creates a "looping effect," whereby the construct of FM is constantly shaped and reshaped (Hacking, 1999; Hazemeijer & Rasker, 2002).

One problem with the theory of the therapeutic domain is that it assumes that the physician-patient relationship is voluntary. Rather, this relationship is a form of social surveillance. Medicine "exercises a hegemonic authority because [its] coercive character is often disguised and masked by [its] normative involvement in the troubles and problems of individuals" (Turner, 1997, p. 24-25). For example, diagnosis is an intervention (Conrad, 2007). This intervention uses technologies, such as blood work, to collect evidence for the purpose of disease identification. These technologies are a form of governmentality, a system of modern day rule, which uses covert mechanisms to exert power over a population (Foucault, 1989). Governmentality shapes, regulates and redirects people's conduct according to certain goals (Chambon, Irving, & Epstein, 1999). In search of abnormality, the medical gaze penetrates through layers of human tissue, blood, and organs. In this Panopticon of diagnosis, the person/patient is placed under medical surveillance: this process is meant to control, validate, and punish (see Foucault, 1995). If the investigation successfully leads to a diagnosis, then the patient's reality is validated. However, if the investigation is unsuccessful in identifying a diagnosis, then the patient may be punished and viewed as a malingerer.

The medical gaze extends beyond the physician's office, policing the person/patient in other social arenas (Foucault, 1989). For example, if a person is diagnosed with an acute illness, she will be temporarily pardoned from her social responsibilities (Parsons, 1951). However, a person who is diagnosed with a chronic condition, such as FM, is not so lucky; if she is unable to

resume her responsibilities, then she will be considered morally suspect, deviating beyond the parameters of the socially acceptable sick role (Parsons, 1951). As a consequence, she may encounter resentment from colleagues, friends, and family who assume that extended lifestyle modifications signify both a character flaw and a poor work ethic (Cunningham & Jillings, 2006; Sylvain & Talbot, 2002). In this light, "health has a moral dimension, reflecting not only the adoption or maintenance of a healthy lifestyle, but also how people respond to illness and deal with its aftermath" (Bury, 2005, p. 9).

The diagnostic construction of FM, which originates in the physician's office, has a contradictory quality. On one hand, medicalization legitimates the person's experience of suffering (Conrad, 2007). On the other hand, medicalization "others" the person, labels her as the opposite of the norm, and punishes her for prolonged impairment (Crooks et al., 2008; Smith, 2002; Ware, 1992). This process is individualizing; because "medical definitions work to categorize people according to specific problems, their focus locates the cause of the problem squarely within the mind /body of the individual" (Crooks et al., 2008, p. 1838). In this sense, a person experiences shame and guilt when her reality of chronic illness conflicts with mainstream "realities" about health and illness (Ware, 1992). Shame and guilt become internalized as technologies of the self (Foucault, 1989).

From Medicalization to Biomedicalization

Although the theory of the therapeutic domain mentions that social institutions influence the construction of disease, it primarily focuses on the physician-patient relationship. Other theorists, however, have argued that during the past few decades, physicians' authority over the medicalization of disease has been diminished by other forces (Barker, 2008; Clarke, Shim, Mamo, Fosket & Fishman 2003; Conrad; 2007). These forces -- including corporate health

industries, biotechnology, media, and patient support groups -- interconnect in "complex, multisited, multidirectional" ways to increasingly medicalize society (Clarke et al., 2003, p. 162). Aging, for example, has become increasingly medicalized as anti-aging interventions, such as Botox and plastic surgery, are normalized. In this light, institutionalized forces have transformed medicalization into "biomedicalization." The "bio" in biomedicalization denotes the ways in which recent innovations, such as those in science and technology, have reorganized society (Clarke et al., 2003, p.162).

The biomedicalization of FM occurs through the interconnected power of insurance and pharmaceutical companies, advertisements and electronic support groups. For example, corporations are in the business of constructing diseases (Moynihan et al., 2002). In fact, disease constructions are a prerequisite for obtaining disability benefits from insurance companies. However, FM was not recognized as an official diagnosis until the Copenhagen Declaration in 1992 (Csillag, 1992). Considering that many people with FM are unable to work (White et al., 1999a), it is possible that economic pressure was one of the factors underlying the Copenhagen Declaration. Although an FM diagnosis makes it easier to obtain insurance benefits, the diagnosis diminishes the agency of people who are unable to work due to chronic illness. They must conform to diagnostic labels in order to receive financial compensation (Crooks et al., 2008).

In addition to insurance companies, pharmaceutical companies contribute to the biomedicalization of FM. They have "corporatized and privatized" biomedical research by funding certain types of studies (Clarke et al., 2003, p. 167). For example, the ACR study, which led to the revised classification criteria for FM, was funded by Lilly Research Laboratories, a detail disclosed in small print on the article's first page (Wolfe et al., 2010). Although this

disclosure statement denied any conflict of interest, it is doubtful that Lilly Research Laboratories did not have overt or covert influence over this study. Consequently, pharmaceutical companies have sway over FM research; how else can one explain the increasing number of publications that report the findings of pharmacological treatment studies?

Another factor that has influenced the biomedicalization of FM is economic risk. FM results in monetary losses for both employers and insurance companies (White et al., 1999b). Pharmaceutical companies offer a remedy to this risk by distributing medications -- a fast, affordable, standardized, and accessible solution -- to help people return to work. As a consequence, these companies contribute to the "McDonaldisation" of health (Turner, 1997). In comparison to the ever-expanding fast food industry, the market for FM medications, despite their side effects, is growing because non-pharmacological treatments have limited efficacy (Wolfe, 2009). In this sense, pharmaceutical companies are disease mongers, "widening the boundaries of treatable illness in order to expand markets for those who sell and deliver treatments" (Moynihan et al., 2002, p. 886).

Pharmaceutical companies work with the media to biomedicalize health. Through the process of marketing medications, for example, pharmaceutical companies attempt to change public perceptions about health and illness (Moynihan et al., 2002). They use direct to consumer (DTC) advertising and other forms of media to generate both fear about illness and interest in new treatments (Moynihan et al., 2002). In turn, the media regulates the flow of information by selecting which narratives will be transmitted for public consumption, thereby influencing the types of knowledge deemed valuable and newsworthy (Barker, 2002; Clarke, 2010; Kroll-Smith, 2003; Lyons, 2000; Phillips, Kanter, & Bednarczyk, 1991). These narratives are insidiously packaged as taken-for-granted knowledge in everyday life (see Berger & Luckman, 1967).

Medication marketing campaigns create and perpetuate taken-for-granted knowledge that pharmacological treatment will lead to physical and emotional well-being. In the case of FM, for instance, advertisements for the medication, Lyrica, display happy, middle-class women whose symptoms have improved due to this pharmacological intervention (Wolfe, 2009). These advertisements target new consumers by sending the message that specific types of people – middle-class women -- are all "at risk" for developing FM. The "at risk" discourse implies that FM is a debilitating yet treatable condition, as long as medication is consumed; medication is both a "micro-regulation" and a micro-level solution, which depends on individual compliance (Turner, 1997). This discourse positions women consumers as morally responsible for managing their condition and complying with their treatment regimens (Clarke, et al., 2003; Conrad, 2007). This morality discourse is interwoven with discourses of individuality, such as "know thyself," "care of the self," and "self-discipline." In other words, women must be "proactive" and "take charge" of their health through daily routines consisting of medication, diet, and exercise (Clarke et al., 2003).

Individuality is not only a discourse, but it is also a value, stemming from the Enlightenment period. These discourses and values about health and illness are internalized as a form of social-surveillance and self-surveillance (Foucault, 1989; Turner, 1997). They "are powerfully, deeply and often invisibly embedded in social and cultural views of what it means to be a person" (Webster, 2002, p. 147). Consequently, discourses and values shape subject positions: the woman with a chronic illness is transformed into the proactive and courageous fighter who overcomes adversity (Kelly & Dickinson, 1997; Turner, 1997). In sum, the media promotes biomedicalization through advertisements. Although DTC advertisements are illegal in

Canada, the reality is that Canadians frequently see American advertisements in magazines and on television. In turn, these advertisements shape discourses, values, and subject positions.

Paradoxically, both individuality and collective action are facets of biomedicalization (Clarke et al., 2003; Conrad, 2007). Often times, people, especially those with contested illnesses, do not receive enough validation or information from physicians (Clarke, 2000). As a consequence, they seek information from support groups (Clarke, 2000) and popular media (Kroll-Smith, 2003). A form of popular media, the Internet offers a wealth of resources and opportunities for collective action. For example, a study of an electronic support group found that people with FM established a collective identity based on the medicalization of their illness (Barker, 2008). Through routine interactions, electronic support group members joined together as "FM'ily" (Barker, 2008, p. 28). They used their shared realities and embodied experiences to validate the existence of FM as a "medical entity," despite the lack of objective biomedical proof (Barker, 2008, p. 30). In addition, they expected their physicians to affirm their diagnosis, a phenomenon described as "physician compliance" (Barker, 2008, p. 23). Physician compliance reinforces the notion that the power of medical professionals is changing and even decreasing, as consumers seek to have their lay expertise validated.

X and Why? The Absence of Sex and Gender in Health Research

FM has become biomedicalized by doctors and patients, insurance and pharmaceutical companies, print and social media. However, the biomedicalized construct of FM is devoid of sex and gender, especially in the context of biomedical research. Because this study explored the ways in which healthcare experiences were mediated by gender, it is important to understand how this variable of difference has been specifically understood in previous studies about FM, as well as in the wider context of health research.

It is not surprising that biomedical research has a history of ignoring variables of difference; sexism and paternalism are rampant in both the fields of healthcare and health research (Greaves, 2012). In reaction to these norms and biases, in the 1960s, the second wave of feminism gave birth to the women's health movement. This movement argued that women's bodies were being over-medicalized through health practices, such as childbirth (Greaves, 2012). In turn, this movement fought for women to have control over their bodies and reproductive rights. The movement also advocated for health researchers to incorporate the variables of sex and gender into their studies (Greaves, 2012).

Despite the efforts of the women's health movement, most research studies still do not integrate the variables of sex and gender into their research design and methods of data collection and analysis (Greaves, 2012). For example, the variable of sex may only be considered in a study that compares differences between biological males and females. In this case, difference is assumed to be a problem, which can be neatly solved, by separating men and women into binary categories and performing statistical measurements (Greaves, 2012). In addition to sex, gender is often ignored. Gender is not only difficult to quantify because it is a social process, but has also become conflated with sex (Greaves, 2012). The systemic practice of excluding the variables of sex and gender in men and women's health research is unethical because "every cell is sexed, every person is gendered."[5] In other words, sex and gender intersect in every aspect of human development, shaping bodies, identities, and experiences (Weedon, 1997).

[5] The phrase "every cell is sexed, every person is gendered" was the name of a 2010 conference held by the Canadian Institutes of Health Research Institute of Gender and Health.

The Discourse of Silence

Discourses are "structures of knowledge and systematic ways of carving out reality" (Chambon et al., 1999, p. 272). Discourses not only involve words, but also silence (Armstrong, 1997). In this light, the silence of sex and gender screams with meaning. This silence perpetuates the dominant discourse that sex and gender are not integral to health research. This silence also provokes questions, such as whose interests are served by the exclusion of these variables?

The silence of sex and gender benefits and preserves the institutionalized norms of the biomedical industry. Biomedicine was founded upon a patriarchal epistemology, which values authority, neutrality, objectivity, and reductionism (White et al., 2001). In this framework, men have been positioned as both the leaders and the subjects of research. Historically, research findings from male bodies have been applied to all bodies (Greaves, 2012). This practice is apparent in the era of biomedicalization, whereby diseases are examined at the micro-level of genes, molecules, and proteins (Clarke et al., 2003). On the surface, because these genes, molecules, and proteins appear sexless and genderless, it may seem harmless to only conduct experiments on male species. However, this harmlessness masks monetary implications. Often times, researchers only conduct experiments on male species because they do not have enough funding to incorporate female species into their studies (Mogil, 2010).

The silence of sex and gender is evident in the biomedical literature about FM. Researchers have acknowledged that “fibromyalgia is a disorder of women, but why that should be is not understood and should be the subject of subsequent research” (Wolfe et al., 1995, p. 26). However, the feminization of FM has not become “the subject of subsequent research.” In 2000, for example, 806 research and review articles about FM were published (Barker, 2005).

Out of these articles, only eight addressed sex-related variables and only three discussed clinical differences between men and women (Barker, 2005).

Unfortunately, not much has changed over the past decade. In a search of the PubMed database, for instance, I retrieved 218 abstracts of FM articles that were published in 2010. In the titles of these abstracts, only 16 contained the word "women," three contained the word "gender," and none contained the word "sex." In addition to the titles, the content of these abstracts -- which reported findings from biomedical studies about exercise, medication, sleep, and pain -- were framed from a genderless and sexless perspective. Although there was one review article about sex and gender, it was not specific to FM; this article reviewed the literature about sexual function and musculoskeletal pain in FM, as well as in other conditions (Rosenbaum, 2010).

The few biomedical articles that discussed sex and gender either had inadequate analyses or methodological flaws. For instance, a study, which compared women with FM and women with Multiple Sclerosis, found that disability was mediated by variables, such as social support and economic status (Phillips & Stuifbergen, 2010). However, the study did not analyze the ways in which these variables intersected with sex and gender. Another study, which compared men and women with FM to healthy controls, examined how past experiences of pain impacted current experiences of pain (Staud, Robinson, & Price, 2010). One of the study's research questions was whether the experience of pain was influenced by sex differences. Confusingly, although both men and women with FM participated in the study, the authors reported that the participants were "unavailable for comparisons" without providing an explanation as to why this was the case (Staud et al., 2010, p. 5). What's more, this study used the term sex without

defining its meaning. It is unclear whether the authors were referring to biological differences or conflating the terms sex and gender, a common occurrence in health research (Greaves, 2012).

The paradox of sex and gender.

The lack of biomedical articles that address sex and gender indicates "clinician researchers have not asked themselves, 'I wonder why so many women have FMS [fibromyalgia syndrome]?' Nor have they asked themselves, 'I wonder if our FMS criteria are themselves sex biased?'" (Barker, 2005, p. 62). Barker (2005) has called "the failure to address such questions" as "the 'present-absence' of sex and gender from the idea of FMS" (p. 62). The concept of "present-absence" is similar to the previously described discourse of silence in health research. Paradoxically, the silence/absence is precisely what makes the topic so vocal/present. This paradox reflects the Foucauldian concept that power grows through invisibility.

By banishing sex and gender, biomedical research has transformed FM into a sexless and genderless neurobiological disorder. This neurobiological construct can be interpreted as an attempt to distance FM from women, in general, and the legacy of hysteria, in particular. This distance is important considering that FM is often labelled a modern day form of hysteria due to similarities in both symptoms and epidemiology (Barker, 2005; Webster, 2002; White et al., 2001). In addition, by attributing FM to underlying sexless and genderless neurobiological abnormalities, biomedical research refutes the claim that chronic illness is caused by character flaws and human weakness, specifically women's weakness (Bury, 2005).

Despite the absence of both sex and gender in biomedical research about FM, their presence lurks in the background. For example, the taken-for granted-assumption that FM is an affliction of women is embedded in medical imagery. An iconic drawing of three nude women -- adapted from Baron Jean-Baptiste Regnault's eighteenth century painting *The Three Graces*

(Musee du Louvre, 2012) -- has been reproduced in FM texts, such as peer reviewed journal articles (Wolfe et al., 1990) and mainstream magazine articles (Pouliot, 2002). This drawing is used to educate patients, professionals, and lay people about FM; black dots, which are scattered on the front, back, and side of the nude figures, represent the location of FM tender points (Oldfield, 2011). Although these drawings are meant for educational purposes, the nude bodies possess an undercurrent of sexuality. In this light, the medical gaze has transformed the FM body into a sexualized, female body. Consequently, the appropriation of *The Three Graces* has fused FM with the feminine, sending the message that only women have this condition. The fact that men also suffer from FM has been buried.

FM: Sex and Gender Differences

Why are more women than men diagnosed with FM? This is a difficult question to answer. There is a not only a "present-absence" of women with FM in the biomedical literature, but also a limited amount of research about men (Buskila, Neumann, Alhoashle, & Abu-Shakra, 2000; Paulson, Danielson, & Norberg, 1999; Paulson, Danielson, & Soderberg, 2002). Nevertheless, an analysis of why FM is a gendered diagnosis can be guided by the literature about gender differences and morbidity rates. Generally speaking, women have lower mortality rates than men, but higher morbidity rates[6] (Barker, 2005; Bury, 2005; Clarke, 1999; Finkler, 1994). This means that women experience more non-fatal illnesses than men, both in developed and developing countries (Finkler, 1994).

Bury (2005) argued that women experience more illness than men due to oppressive gender roles. Patriarchal societies create and perpetuate domestic, economic, and legal

[6] These generalizations are not meant to group all women into one category and men into another, thereby ignoring the plurality of people's social locations. For the purpose of analysis, however, I am trying to elucidate the reasons why more women than men have a diagnosis of FM.

inequalities. In turn, these systemic inequalities or "life's lesions" lead to the experience of illness (Finkler, 1994). In other words, illness is a language of oppression that is expressed through the body. Similar to Bury, Verbrugge (as cited in Finkler, 1994) outlined five reasons for the differences in morbidity rates:

> (1) biological risks; these are intrinsic genetic and hormonal differences between males and females, (2) acquired risks; these are risks of illness and injury encountered in one's work and leisure activities, (3) psychosocial aspects of symptoms and care; called 'illness behavior' in medical sociology, (4) health reporting behaviour; this concerns how men and women talk about their health problems to others, and (5) prior health care; or how one's care for health problems affects future health.

This biopsychosocial framework can be applied to FM.

Biological risks.

More women than men may be diagnosed with FM due to biological risk factors and sex differences in genetics and physiology. Studies have found that women with FM report a greater number of symptoms than men with FM, as well as more severe symptoms such as pain (Yunus, 2001). Researchers who study the subject of pain have discussed that sex differences potentially impact how pain is processed in the central nervous system, the autonomic nervous system, and the HPA axis (Fillingim & Maixner, 1995). Furthermore, it is thought that hormones such as estrogen may contribute to pain whereas androgens such as testosterone offer protection from pain (Yunus, 2001). For example, a study found that premenopausal and postmenopausal women with FM had lower androgen levels than healthy controls (Dessein et al., 1999). These low androgen levels were correlated with poorer health status although a causal relationship was not determined. In addition to neurochemicals and hormones, genetics may lead to biological

differences regarding pain. For example, animal experiments have found that females inherit different pain-related genes than males, and therefore may be genetically predisposed to the experience of pain (Yunus, 2001).

Psychosocial aspects.

Biomedical studies have suggested that women are hardwired to experience more pain than men (Yunus, 2001). This evidence helps to explain why women tend to have more severe FM symptoms. However, sex differences alone cannot account for illness severity; culture also plays a role. In North America, for example, population and clinic studies found that women with FM had more severe fatigue and pain than men with FM (Wolfe et al., 1995; Yunus, 2001). In contrast, an Israeli study, which examined FM and gender differences in a tertiary care clinic, found that men had worse symptoms, reduced physical functioning, and poorer quality of life compared to women (Buskila at al., 2000). Men's poor quality of life was related to unemployment, a consequence of disability. In other words, illness leads to economic inequalities, as "those with better health move up the employment ladder over time, and those with poorer health move down" (Bury, 2005, p. 25). Apparently as a result of these inequalities, the men in the Israeli study experienced depression and low self esteem (Buskila et al., 2000). They suffered because they were not the breadwinners, and therefore could not meet the institutionalized expectations associated with traditional gender roles and masculine identities.

In theory, the men in both the American and the Israeli studies should have experienced similar health and employment trends. However, the American men may not have been as ill as the Israeli men, and therefore they may not face the same economic consequences. The variation between samples could also be attributed to the distinct cultural context of each country. Furthermore, the studies could have obtained different findings because they used different

methodologies. Nevertheless, these studies have highlighted that health patterns are mediated by complex factors, including sex, gender, culture, geography and socio-economic status.

Help-seeking behaviours.

More women than men may be diagnosed with FM because of variations in help-seeking behaviours. For example, women are more likely than men to report chronic illnesses, seek medical support, and utilize healthcare resources (Bury, 2005; Clarke, 2012; Yunus, 2001). Women may utilize healthcare services because, as primary care givers, they have more frequent contact with these services (Bury, 2005). In comparison, men are more likely to cope with illness by participating in high-risk behaviours, such as abusing substances (Clarke, 2012). A study found that men with FM postponed seeking medical care because they did not want to be viewed as "whiners" (Paulson, Norberg, & Danielson, 2002). Given these facts, it is possible that men with FM symptoms either delay diagnosis or remain undiagnosed because they do not access healthcare services.

Health reporting behaviours.

In addition to help-seeking behaviours, more women than men may be diagnosed with FM due to differences in their health reporting behaviours. For example, women are socialized to express their symptoms and to be aware of their bodily experiences (Bury, 2005; Clarke, 2004; Yunus, 2001). In contrast, men are less spontaneous in their expression of feelings and have more difficulty describing their symptoms (Paulson et al., 1999). This process of illness expression begins in childhood, as illustrated by a study of hospitalized and non-hospitalized latency-aged children (Savedra, Gibbons, Tesler, Ward, & Wegner, 1982). This study found that more girls than boys used affective language in their descriptions of pain (e.g. pain made them feel "sad").

Gender roles shape methods of health reporting, as well as the ways in which health reporting is interpreted by healthcare professionals. For example, many authors have described that women perceive physical symptoms differently than men, "over-report" somatic complaints, and "catastrophize" their pain (Hazemeijer & Rasker, 2002; Jensen, 1994; Yunus, 2001). These descriptions highlight how health reporting behaviour is stereotyped as gendered behaviour. Consequently, women may be diagnosed with FM because their expression of symptoms is associated with femininity. Conversely, men who present with similar symptoms, but express themselves with less affect than women, may be diagnosed with a different disorder (Paulson et al., 1999). Doctors are also "cautious when they give a diagnosis of FM to men simply because it can be preconceived as being unmanly" (Paulson et al, 1999, p. 1101). Furthermore, men may associate self-expression with femininity, and therefore underreport their symptoms in order to preserve the appearance of masculinity (Bury, 2005; Yunus, 2001).

The Intersectionality of Difference

This chapter has framed FM as a biomedicalized and gendered construct. Although it is important to address gender and health, a gendered framework can ignore how other forms of embodied and socially-located differences impact the experience of illness (Dhamoon, 2001). It is crucial for researchers to develop a framework for understanding how systems of embodied differences, such as race, class and culture, intersect in the healthcare experiences of men and women with FM. The FM literature has not yet addressed systems of embodied differences. Thus, I have turned to the feminist literature on intersectionality in order to conceptualize the nuances and complexities of difference.

In the 1970s, black feminist scholars argued that the women's movement was dominated by white, middle-class women who marginalized black women and women living in

"developing" countries (Ludvig, 2006). As a response, in the mid 1980s, scholars moved away from viewing men and women as binary categories and began to explore the differences within these categories (Ludvig, 2006). In order to examine difference, scholars took an additive approach by adding race and class to gender (Mehrotra, 2010). This additive approach conceptualized race, class, and gender as a "triple oppression" (Yuval-Davis, 2006, p. 194). In other words, this approach viewed race, class, and gender as separate and essentialized identities, which were neither integrated nor given equal weight.

In the 1980s and 1990s, scholars -- including Angela Davis, Audre Lorde, and Patricia Hill Collins -- theorized about identity politics, namely the experiences of marginalized populations. These scholars deconstructed the homogeneous construct of black women, exploring differences both across and within groups (Prinns, 2006). In 1989, this exploration of difference was named "intersectionality" by the American critical race scholar Kimberle Crenshaw (Hankivsky, Cormier, & de Merich, 2009). Although intersectionality does not have a singular definition, it posits that identities and experiences are heterogeneously shaped by intertwined and shifting elements (Dhamoon, 2011; Mehrotra, 2010).

> Broadly speaking, this perspective moves beyond single or typically favoured categories of analysis (e.g., sex, gender, race, and class) to consider simultaneous interactions between different aspects of social identity (e.g., race, ethnicity, Indigeneity, gender, class, sexuality, geography, age, ability, immigration status, religion) as well as the impact of systems and processes of oppression and domination (e.g., racism, classism, sexism, ableism, homophobia). (Hankivsky et al., 2009, p. 3).

The purpose of the identification of intersectionality is the promotion of social justice through an exploration of the ways in which categories of difference are produced and reinforced by individuals and institutions (Hancock, 2007).

Institutions operate within systems of power and oppression, "the matrix of domination" (Collins, 1990), and are constantly shifting over time, space and place (Hankivsky & Cormier, 2011). However, where there is power, there is also resistance. Intersectionality enables examinations of how a person is "being subjected to" while simultaneously participating in "becoming a subject" (Prins, 2006, p. 280). This process of "becoming a subject" involves the power to "narrate" or describe the contradictory and layered ways in which identities are "embedded" within social contexts (Prins, 2006, p. 281).

Although intersectionality provides valuable insights about difference, this concept has several limitations. First, some scholars, who apply theories of intersectionality, reduce and oversimplify identities, isolating them outside of their historical contexts (Dhamoon, 2011, p. 233). Second, a review of intersectionality studies conducted between 2000 and 2008, found that the majority of these studies analyzed the categories of race, class, and gender, while only a limited number of studies explored categories, such as ability, age, religion, and sexual orientation (Hulko, 2009). Third, scholars have conflicting opinions as to whether intersectionality theorizing should solely focus on marginalized identities or whether it is valid to focus on identities of privilege (Mehrotra, 2010). Fifth, scholars have had difficulty illustrating the concept of intersectionality. Sixth, scholars have inconsistently described intersectionality as a lens, theory, framework, paradigm, and perspective (Mehrotra, 2010). Finally, scholars lack a consistent methodology for carrying out intersectionality analyses in empirical research (Ludvig, 2006). One implication of inconsistent methodologies is that policymakers often look to

evidence-based research for direction in the development of policies. However, policymakers are hesitant to develop policies pertaining to issues of intersectionality given the lack of analytic guidelines and best practices (Hankivsky & Cormier, 2011).

Given the methodological limitations of intersectionality, I have not applied intersectionality in a specific step-by-step manner for data analysis. Instead, I have used intersectionality as a conceptual compass to help guide: a theoretical understanding of the ways in which systems of embodied differences impact men and women's healthcare experiences; and, an interpretation of analytic codes emerging from the data. By conceptually applying intersectionality to FM, men and women with this condition are viewed as inhabiting an endless array of overlapping subject positions based on their gender, sex, class, race, culture, age, ability, sexual orientation, and religion. These systems of embodied differences are impossible to separate and instead intersect to shape ever-changing identities and experiences.

Chapter Summary: From Constructing FM to Deconstructing Gender and Systems of Embodied Differences

In this chapter, I have outlined the theoretical framework of the dissertation study by synthesizing the literature on social constructionism, medicalization, biomedicalization, feminism and intersectionality. This theoretical foundation is based on the premise that the diagnosis of FM has been shaped by interconnected social forces, including doctor-patient relationships, corporatization, pharmaceutical companies, advertisements, and social media. These forces are intertwined in what it means to be a patient with FM seeking diagnosis, undergoing treatments, and living with a chronic condition. Furthermore, what it means to be a patient with FM varies between people. Systems of embodied differences -- including gender, age, class, culture, and race -- and their accompanying norms and discourses are internalized by

people, thereby shaping experiences and subject positions. As such, people's healthcare experiences, as well as the meanings that they attach to these experiences, should be understood within the larger social, political, economic, and cultural context.

CHAPTER THREE – LITERATURE REVIEW CONTINUED

A SOCIAL HISTORY OF FM'S BIOMEDICAL ILLEGITIMACY

Figure 4: Hope's body map.

I introduce this chapter with Hope's body map because she depicted the quest for biomedical legitimation. Hope represented her healthcare journey as a game of snakes and ladders: she would climb towards the goal of diagnostic relief only to slide down a winding, vicious and, at times, venomous path of biomedical skepticism. Hope's imagery of illegitimacy reflects how FM is an elusive condition that continues to defy medicalization.

In the previous chapter, I argued that FM is a socially constructed condition. However, my argument would probably exasperate Ian Hacking, a Canadian philosopher. Hacking (1999) critiqued the tiresome trend of everybody describing everything as socially constructed. According to Hacking, we must move beyond this ideological conformity by inquiring *what* is being constructed and *why*, as well as *who* is potentially benefitting from this construction. Inspired by Hacking's line of inquiry, the purpose of this chapter is to synthesize the biomedical literature on FM in order to understand *why* FM has been both constructed and reconstructed and to question *who* benefits by these (re)constructions. In this chapter, I argue that FM was constructed by the field of rheumatology in an attempt to medicalize a constellation of elusive symptoms. The goal of medicalization was to contain the elusiveness of these symptoms within a fixed category and to *objectively* distil the essence and underlying etiology of these symptoms. However, rheumatology has not identified the etiology of FM and has subsequently relinquished professional responsibility for this condition. I posit that this biomedical uncertainty has contributed to the continued illegitimacy of FM, as well as to the marginalization of people suffering from this unsuccessfully medicalized condition. In the last section of this chapter, in order to further explore these themes of illegitimacy and marginalization, I review the qualitative literature about patient and healthcare providers' experiences of FM.

The biomedical literature on FM has slowly grown over the last hundred years. The PubMed database, for example, contains 6579 references for FM journal articles published between 1913 and 2011[7]. This body of empirical literature includes studies about epidemiology, causation, and treatments. Several articles have also reviewed the history of FM in order to understand a misunderstood condition (Clauw & Crofford, 2003; Inanici & Yunus, 2004; Peterson, 2007; Powers, 1993; Wessely & Hotopf, 1999; White & Harth, 2001). Before delving into this literature, it is helpful to contextualize FM within the paradigm of biomedicine.

The Biomedical Paradigm

Between the late 1800s and early 1900s, the biomedical paradigm gained credibility within the medical community as a method of scientific inquiry (Barker, 2005). Biomedicine is "medical practice based on the principles, methods, and technologies of the biological life sciences, and it has tremendous cultural authority in matters of illness" (Barker, 2005, p. 10). This authority has been gained through the construction of disease, a historical practice whereby scientists have classified physiological abnormalities in the same manner as plant and animal species. In this paradigm, "diseases have an existence independent of the observer and exist in nature, ready to be 'discovered'" (Smith, 2002, p. 883-884).

The idea of discovery is connected to the assumption that every disease has a specific etiology. According to this line of reasoning, symptoms can be traced backwards to pathology and then to an underlying cause (Bury, 2005). This underlying cause is discovered by clinician-researchers who poke and prod the body with tools and tests, searching for the pathology that lurks within tissue, organs, blood, and genes (Holmer Nadesan, 2005). Consequently, clinician-researchers have microscopically reduced diseases to the biology of cause and effect, rather than

[7] In this advanced search, I used the keywords fibromyalgia, fibromyalgia syndrome, and fibrositis because these three terms have historically referred to the same condition.

examining them as a kaleidoscope of biological, social, psychological, and environmental factors (Morris, 1998). This reductionism creates order and containment while masking the values and interests of a particular culture at a particular time (Barker, 2005; Holmer Nadesan, 2005; Whitmarsh, 2008).

Paradigms, Professional Status, and Pain

The biomedical paradigm shapes the objectives and status of medical specialities. For example, studies have found that the medical community ranks specialties on a hierarchy of prestige (Album & Westin, 2008; Hinze, 1999; Rosoff & Leone, 1991). This prestige is related to the amount of biomedical certainty provided by each specialty. On the prestige hierarchy, specialties such as neurosurgery are ranked the highest because they have a clear agenda: they utilize technologically sophisticated interventions in order to treat acute diseases and repair major organs. In comparison, chronic disease specialties are ranked the lowest because their scope of practice has greater ambiguity (Album & Westin, 2008). For example, rheumatology, a branch of internal medicine, has relatively low prestige because it specializes in both the treatment of complex musculoskeletal disorders and the management of pain (Barker, 2005).

Rheumatologists are inundated with referrals to assess and treat pain, a common symptom of many rheumatic conditions (Wolfe, 2009). Modern conceptualizations of pain emerged during the Renaissance period with the "birth of the individual". Pain was conceptualized as a pathology existing within the individual that led to suffering (Eccleston, Williams & Stainton Rogers, 1997). However, the concept of pain is problematic; it is a subjective expression of an internal experience, a phenomenon that is difficult to objectively measure. Clinicians attempt to "trace pain backwards... to the true object of biomedicine: the organic condition producing the experience of pain" (Barker, 2005 p. 19). Unfortunately, this is

often an exercise in futility. When clinicians cannot find an underlying condition their practice becomes limited to symptom-based treatments, which do not always alleviate pain. Because treating pain is an inexact science, it does not garner status in the medical hierarchy (Barker, 2005). In this light, "Although pain stands at the margins of biomedicine, it stands at the centre of rheumatology. In effect, pain has become the conceptual justification for rheumatology" (Barker, 2005, p. 19).

Rheumatology's Failed Attempt to Medicalize FM

Although FM is not viewed as a musculoskeletal disorder, the hallmark of this condition is muscle and joint pain. Consequently, FM has historically fallen under the jurisdiction of rheumatologists. During the 1980s, several rheumatologists became the "diagnostic entrepreneurs" of FM (Barker, 2005, p. 23). These rheumatologists included Robert Bennett (Oregon Health Sciences University), Don Goldenberg (Boston University School of Medicine), Frederick Wolfe (University of Kansas Medical School), and Muhammad Yunus (Peoria School of Medicine). They assumed a leading role in biomedical research about FM, as well as in the clinical care of those afflicted with this disorder (Barker, 2005). Bennett, Goldenberg, Wolfe, and Yunus alongside their respective research teams conducted case-controlled clinical research studies in order to understand the characteristics of FM (Barker, 2005).

The attempts of these "diagnostic entrepreneurs" to medicalize FM had numerous practical implications. First, by positioning FM as a valid diagnosis within the biomedical paradigm, rheumatologists could categorize and therefore contain throngs of patients suffering from chronic and ambiguous musculoskeletal pain. Second, this classification could legitimize ambiguous pain, and therefore provides patients with emotional relief (Goldenberg, 1999; Wessely & Hotopf, 1999). Third, this classification could allow rheumatologists "to avoid

dealing with psychosomatic issues," a topic that was historically excluded from medical discourses, literature, and training (Wolfe, 2009, p. 5). Fourth, because rheumatologists transformed the vagueness of pain into a formal diagnosis, they could venture on a quest for a "socially acceptable" etiology of pain. If a physical etiology was found, then rheumatology could potentially bolster its status as a legitimate discipline (Wolfe, 2009).

Despite rheumatology's intentions, biomedical constructions of FM have continually changed. Since the early 1900s, for example, the biomedical literature reveals shifts in the: (a) terminology used to describe the constellation of symptoms currently called FM; (b) categorization of people with FM; (c) meanings of FM; (d) criteria used to classify FM for research and clinical purposes; (e) conflicting empirical understandings of FM; (f) direction of research; and (e) role of rheumatology in caring for the FM patient population.

Shifting terminology.

In the context of biomedicine, naming diseases formalize their existence (Brown, 1995; Conrad, 2007). The act of naming is part of the process of medicalization, whereby ambiguous yet common symptoms, such as pain and fatigue, are transformed into a diagnostic category (Barker, 2008). Over the last 100 years, however, the constellation of symptoms currently known as FM have been named and renamed. In 1904, the medical literature, which has discussed muscle pain for centuries, introduced the concept of FM (White & Harth, 2001). FM was originally called fibrositis, a term coined by the British neurologist Sir William Gowers (Inanici & Yunus, 2004). Gowers (1904) used the term fibrositis -- meaning inflammation of fibrous tissue -- to describe localized musculoskeletal pain, which was accompanied by fatigue and sleep disturbances and aggravated by cold weather and physical strain. Future scholars argued that fibrositis was an erroneous term because fibrous tissue could not become inflamed. Nevertheless,

for several decades scholars used this term in order to describe muscle and joint pain of unknown origin (Inanici & Yunus, 2004). During this time, fibrositis was also called fibromyositis, myofascitis, myofibrositis, neurofibrositis, psychogenic rheumatism, myofascial pain syndrome, and interstitial myofibrositis (Inanici & Yunus, 2004; Yunus, Masi, Calabro, Miller, & Feigenbaum 1981).

In 1976, the rheumatologist P. K. Hench renamed fibrositis FM because it provided a more accurate description of the condition's symptoms (Inanici & Yunus, 2004). The term was derived from the Latin roots "fibro" (fiber), "myo" (muscle), "algos" (pain), and "ia" (condition) (Powers, 1993, p. 93). In 1990, the American College of Rheumatology (ACR) adopted FM as the condition's official name in order to establish a consistent vocabulary within the medical community (Wolfe et al., 1990).

FM's changing terminology is not only confusing, but also raises many concerns. For example, it is unlikely that all of FM's previous terms referred to the same group of people, the same symptoms, and the same condition (Russell, 1999). Furthermore, it is questionable whether a condition can be accurately categorized when the cause is unknown (Larson & Kovacs, 2001). It can also be argued that naming is an act of desperation to label, and therefore contain and control people with ambiguous pain. This label has not reduced the amount of suffering or improved people's quality of life (Wolfe, 2009). Consequently, these concerns highlight that FM's terminology did not lead to diagnostic certainty; scholars still question what FM means and what makes it unique from other generalized pain conditions. In fact, the "only certainty in fibromyalgia is that it is still being diagnosed" (Hazemeijer & Rasker, 2002, p. 512).

Shifting categorizations of people.

In addition to diagnostic terms, categories of people are socially constructed (Hacking, 1999). Although researchers have attempted to understand the demographics of people with FM, there are shifting views about who is afflicted with this condition. For example, Canadian and American general population surveys have found that on average FM is more prevalent in women over the age of 50 than in men over this age (White et al., 1999c; Wolfe et al., 1995). This group tends to: be divorced, lack postsecondary education, have low incomes, suffer from depression, and have family histories of affective disorders (White et al., 1999c; Wolfe et al., 1995)[8]. This group does not only exist in North America; people with FM are found in diverse countries, including Mexico, Poland, and Pakistan (White & Harth, 2001).

Interestingly, the category of people with FM, which has been defined by researchers, contradicts the category constructed within popular culture. For example, in a study about the representation of FM in North American magazines, Dr Juanne Clarke and I found that people with FM were portrayed as white, educated, middle-class, working mothers (Skop & Clarke, 2013). Ironically, this representation is similar to Freud's description of women who suffered from hysteria. Consequently, which representation do we either accept or deny? Are people with FM: (a) aging, multicultural, lower-class, and depressed women; (b) white, middle-class mothers; or (c) both? The contradictions within this category we call "people with FM" highlight how classifications are pliable and ever-shifting.

Shifting meanings.

Like the changing vocabulary and categorization of people, the meanings associated with FM have shifted overtime. These shifts have made it difficult to establish a unified concept of

[8]These findings echo the broader trends in health research; in general, illness is associated not only with gender, but also with poverty, low education, and old age (Bury, 2005).

FM. Since the 1930s, for example, there have been competing theories about whether FM is either an organic or psychosomatic condition (Wessely & Hotopf, 1999). During World War II in British and American army hospitals, clinicians considered FM to be a psychosomatic illness called psychogenic rheumatism. This diagnosis was given to shell-shocked patients who experienced depression and anxiety and complained of rheumatism, but did not display the expected signs of inflammation and muscle degeneration (Inanici & Yunus, 2004). Over the next few decades, the assumption that FM was psychosomatic prevailed within the medical community; there was a lack of research proving otherwise (Barker, 2005).

During the early 1970s, there was a revolt against a psychosomatic conceptualization of FM and a push towards a biological understanding. In 1972, the Canadian rheumatologist Hugh Smythe argued that FM was a legitimate and non-psychiatric medical condition. He provided the first modern definition of FM as a physical condition consisting of widespread pain and tender points[9] (Wesseley & Hotopf, 1999). Smythe proposed that these tender points could become criteria for diagnosis, thereby transforming a collection of vague symptoms into a clinically identifiable condition (Barker, 2005). During the late 1970s and 1980s, Smythe's criteria piqued the interest of researchers who began examining whether FM was a distinct organic condition (Barker, 2005; Inanici & Yunus, 2004; Wessley & Hotopf, 1999).

Smythe's influence in the field of FM research could have been related to the inadequacy of the existing psychosomatic paradigm, which was unable to address the needs of FM patients and practitioners. By viewing FM through a biomedical lens, Smythe's contemporaries -- including rheumatologists Bennett, Goldenberg, Wolfe, and Yunus -- could utilize established biomedical research tools in order to search for the cause of the condition. For example, prior to

[9] Tender points (also referred to as trigger points, nerve points, and nodules) are located over the muscles, as well as over the areas where the muscles connect with tendons and bones (Peterson, 2007, p. 342).

the 1980s, biomedically *valid* and *reliable* research methodologies, such as case-controlled clinical studies, were missing from the FM literature. However, case-controlled studies were considered an important methodology for examining FM's characteristics and prevalence in normal populations (Yunus et al., 1981). As a consequence, during the 1980s, Bennett, Goldenberg, Wolfe, and Yunus filled this gap by conducting case-controlled studies about the clinical characteristics of FM (Yunus et al., 1981), juvenile FM (Yunus, 1984), and the efficacy of medications (Bennett et al., 1989; Carette, McCain, Bell, & Fam, 1986). Although these rheumatologists respectively used case-controlled studies to legitimize FM, they used inconsistent methodologies and applied different criteria, such as the number of tender points required to classify research participants (Barker, 2005). These discrepancies created confusion about what characteristics constituted FM.

Shifting classification criteria.

The ACR's 1990 consensus definition and diagnostic criteria.

As remedy to the confusion about FM characteristics, the ACR established the Multicenter Criteria Committee in 1986. The objective of the Committee was to develop a consensus definition of FM and unified classification criteria. The Multicenter Criteria Committee conducted a multi-site study of 558 patients (193 people with FM and 265 controls) across 16 North American medical sites (Wolfe et al., 1990). They found that tender points could be used to differentiate FM from other rheumatic conditions. Based on these findings, the Committee agreed that FM could be classified via: (a) patient report of chronic widespread pain lasting longer than 3 months; and (b) patient identification of pain in 11 out of 18 tender points

via physical examination[10]. The Committee expected that the classification criteria would be applied by researchers in clinical and epidemiological investigations, as well as by clinicians for patient diagnosis (Wolfe et al., 1990).

The classification criteria can be interpreted as the ACR's "endorsement" of FM. This authoritative body formalized the condition, thereby providing it with "academic respectability" (Wolfe, 2009, p. 5). It is, therefore, not a coincidence that only two years after the criteria's publication, FM became an official diagnosis. FM's new status was announced in the "Copenhagen Declaration," a statement issued in Denmark at the 2nd World Congress on Myofascial Pain and Fibromyalgia (Csillag, 1992). This diagnosis was also incorporated into the World Health Organization's tenth revision of the International Statistical Classification of Diseases and Related Health Problems (Csillag, 1992). According to Bury, "Many diseases can properly be recognized only by referring to a set of criteria (often arrived at by international groups of doctors) rather than identifying one underlying factor; diagnosis is often probabilistic rather than definitive" (2005, p. 5). In this light, both the classification criteria and the formalization of the diagnosis reified FM as a biomedical entity.

The 2010 revisions to the ACR's diagnostic criteria.

Although the ACR's 1990 criteria were widely adopted by rheumatologists for diagnostic purposes, the validity of the criteria was challenged. One critique was that the ACR's definition of FM was tautological because "tender points both define and substantiate its existence" (Barker, 2005, p. 25). Another critique was that the criteria did not account for symptoms other than pain. In addition, the accuracy of the FM diagnosis was questioned because it depended on

[10] During physical examinations, clinician-researchers were instructed to use their thumbs and fingers to apply four kilograms of pressure to patients' tender points, measuring both the amount and the rate of pressure with an instrument called a dolorimeter (Wolfe et al., 1990).

peoples' subjective accounts of their illness histories. A further problem was that primary healthcare physicians were not consistently or correctly conducting tender point exams and, when these exams were conducted, they did not always capture patients with mild pain (Wolfe et al., 2010).

To remedy these problems, in 2010, the ACR proposed revised diagnostic criteria based on the findings of a multicentre study (Wolfe et al., 2010). The new criteria employed scales for assessing pain and symptom severity based on patients' subjective reporting, while deleting the tender point exam. Some modifications were proposed in 2011 (Wolfe et al., 2011). Both the tender points exam and the symptom severity scales are subjective measures based on patient reporting. However, the benefit of the tender points exam is that it is a visual reference for the invisibility of pain and is the only clinical evidence of FM's existence; specifically, the tender point exam involves the physician noting the location of the patient's pain on a visual chart based on the patient's report.

By removing the tender point exam and not substituting another physical test, the ACR's 2010 criteria have delegitimized FM. Narrowly, removing the tender point exam implies that FM is not a musculoskeletal disorder, and therefore not within the domain of rheumatology. More broadly, the removal might be suggesting that FM is not a physical illness, meaning it is the antonym of physical illness: mental illness. Furthermore, the looseness of the new criteria may capture people suffering from symptoms that look like but are not the same as FM. Having a heterogeneous definition is problematic for research because treatments may work for some parts of the cohort and not others, confusing the findings. The broad definition also reinforces FM's reputation as a wastebasket diagnosis and reduces the condition's credibility.

Comparison of the 1990 and 2010 criteria.

The 1990 criteria and the 2010 criteria define overlapping but different groups. On one hand, the 2010 criteria identified 88.1% of people previously classified using the 1990 criteria (Wolfe et al., 2010). That means that 12% of people who qualified under the 1990 criteria would not qualify under the 2010 criteria. On the other hand, there are people who would qualify under the 2010 criteria but not under the 1990 criteria. The extent of this is not clear.

It is fair to question whether changing the criteria had underlying financial motivations; a diagnosis once intended for legitimation is now imposing "large economic burdens on society" (Clauw, Arnold & McCarberg, 2011, p. 907). These "burdens" have impacted both the healthcare system and insurance companies. For example, a survey of Canadian insurance company records found that a diagnosis of FM was associated with 9% of all disability payments, which annually cost $200 million (White, Speechly, Harth, & Ostbye, 1999). In this context, switching criteria could help insurance companies save money. For instance, insurance companies could ask claimants, who were diagnosed under the 1990 criteria, to re-qualify for their disability insurance. If these claimants do not fit within the 2010 diagnostic criteria or simply do not make it through the administrative process of re-qualifying, then they could lose their insurance benefits.

It is important to contextualize the power of doctors and insurance companies in shaping Western discourses about illness and insurance benefits. Schaffner (2001) explained that in 1884, industrial-era Germany passed the law of accident insurance, thereby bestowing doctors with the power to assess patients' work-related injuries and entitlement to employment insurance. At this time, there was a paradigmatic shift whereby the medical gaze turned from the body to the mind. By resituating the gaze, doctors posited that workplace accidents led to "psychic trauma," which

in turn prompted disability claims (Schaffner, 2001, p. 85). Moreover, doctors were concerned that accident insurance would normalize the social acceptability of injuries and increase the discourse of workplace risk. In order to regulate this risk, doctors argued "that insurance itself and not the accidents produced traumatic neurosis" and therefore framed traumatic neurosis as "pension neurosis" (Schaffner, 2001, p. 89). This framing provided doctors with justification to deny patient requests for insurance benefits.

Fast forward to the present day, Western medicine's legacy of situating bodily illness within the mind continues. As previously described, by removing the tender points exam, the 2010 criteria shifts the gaze away from the body to the mind, thereby reinforcing the discourse that FM is a psychosomatic condition. This discourse implies that people with FM are physically capable of maintaining employment, and thus they do not morally deserve insurance benefits. This discourse provides insurance companies with a rationale for controlling the increasing number of disability claims by denying benefits or, at the very least, making the claims process more challenging for people with FM.

Alongside the insurance companies, the pharmaceutical industry may potentially benefit from the shifting diagnostic criteria. Medications, such as antidepressants (which operate to reduce and manage symptoms of pain), are widely advertised and prescribed for people with FM. However, many people with FM do not take these medications on a long-term basis due to the lack of benefits and/or negative side effects (Lunn, Hughes & Wiffen, 2011; Moore, Straube, Wiffen, Derry, & McQuay, 2010). However, a cohort of people diagnosed with FM under the 2010 criteria may have a different response to the medications because their symptom profiles may differ from the 1990 cohort.

Ultimately, the shifting diagnostic criteria benefits the medical model by reinforcing its underlying Cartesian philosophy of mind-body dualism. In theory, the FM diagnostic criteria could integrate the tender points exam with the symptom severity scales, thereby creating a holistic method of mind-body assessment based on both patient reports and physical tests. However, by replacing the tender points exam with subjective scales, the ACR reinforces the false biomedical dichotomies of objectivity-subjectivity and body-brain.

Shifting empirical understandings.

As previously described, one of the objectives of the ACR's 1990 classification criteria was to establish consistent methodological approaches in FM research. Despite the criteria, however, biomedical researchers remain divided and uncertain about the possible cause of FM. This divisiveness has been reinforced by the Cartesian philosophy of mind-body dualism, which underlies the biomedical realm. Cartesian dualism is reflected in researchers' epistemological stances: some biomedical researchers have conceptualized FM as a disease of the body whereas others have relegated it to the realm of psychosomatic medicine (White & Harth, 2001; Winfield, 2000). Ironically, psychosomatic medicine, which was originally intended to integrate the mind and body, has become synonymous with psychiatric disorders, thereby reinforcing biomedicine's Cartesian dualism (Ware, 1992, p. 356). Although biomedical researchers are divided in their views of causation and have distinct research agendas, the positions of each group overlap (Barker, 2005). For example, some researchers strictly posit that FM is a physiological entity while other researchers hypothesize that FM is caused by overlapping biological, psychological, and social variables (Abeles, Pillinger, Solitar, & Abeles, 2007; Goldenberg, 1999; Winfield, 2000). Indeed, some authors have argued that FM exists within "that grey area between medicine

and psychiatry that is also occupied by chronic fatigue syndrome, irritable bowel syndrome, and many others" (Wessely & Hotopf, 1999, p. 430).

Virology.

Researchers who hypothesize that FM is located in the body have searched for FM's pathophysiology. This search has covered the diverse geographies of virology and muscle metabolism, sleep patterns and neurochemistry (Block, 1999; Peterson, 2007). However, many of these empirical expeditions have been unsuccessful. For example, many people have self-reported suffering from viral infections prior to the onset of FM (Goldenberg, 1999). Research studies, however, have not found evidence of a causal relationship between FM and viral infections, such as the Epstein-Barr virus or Lyme disease (Buchwald, Goldenberg, Sullivan, & Komaroff, 1987). Despite these findings, some researchers continue to suspect that exposure to infections is a predisposing factor in the onset of FM (Goldenberg, 1988; Goldenberg; 1993; Goldenberg, 1999).

Muscle metabolism.

In addition to virology, research studies have examined muscle metabolism as a possible explanation for FM. During the 1980s, for instance, several studies found abnormalities in the muscle tissue of people with FM (Bengtsson, Henriksson, & Larsson, 1986; Bennett et al., 1989; Holloszy & Coyle, 1984). However, these studies were methodologically flawed; people with FM were not matched with healthy controls based on their fitness level, an important variable that impacts muscle conditioning (Abeles et al., 2007; Block, 1999). Although subsequent studies have not found evidence of muscle abnormalities in people with FM (Yunus, Kalyan-Raman, Masi, & Aldag, 1989), some researchers have continued to investigate this subject (Kim, Jang & Moon, 2006).

Sleep disturbance.

Another inconclusive line of inquiry has involved the role of sleep quality. Since the 1970s, for example, studies have found an association between FM and disturbances in stage-four sleep (Drewes, 1999; Drewes et al., 1995; Moldofsky, Scarisbrick, England, & Smythe, 1975). This stage of deep sleep helps the nervous system to function by resetting the body's neurochemical processes and producing a growth hormone required for the repair of muscle tissue (Peterson, 2007). The problem with this line of inquiry is that sleep disturbance is not unique to FM; it is also a symptom of other illnesses. Furthermore, a causal relationship between sleep disturbance and FM has not been proven (Wessely & Hotopf, 1999).

Neurobiology.

During the 1970s and 1980s, researchers working in the areas of virology, muscle metabolism, and sleep patterns could not find the cause of FM. By the early 1990s, however, a growing number of researchers turned their attention to a possible link between FM and central pain processing (Abeles et al., 2007). Mounting empirical evidence has indicated that people with FM have abnormalities in central pain processing. Metaphorically, they have a raised "volume control setting for pain" (Clauw, Arnold, & McCarberg, 2011, p. 908). They feel pain from normally non-painful stimuli, as well as amplified pain from normally painful stimuli (Abeles et al., 2007). Consequently, researchers have conceptualized FM as a neurobiological disorder, involving "an abnormality with nocicpetion, the process by which painful stimuli are transmitted neurochemically between the peripheral and central nervous systems" (Barker, 2005, p. 30). This conceptualization is based on the premise that an unknown part of the body's pain perception system -- which includes the brain, neurotransmitters, spinal cord, and peripheral

nerves -- is short-circuiting (Barker, 2005). In other words, the body is sending, receiving, and processing faulty pain signals.

Researchers have theorized that faulty pain signals are related to the phenomenon of "wind up". In short, wind up is the "the neurochemical outcome of chronic pain" (Barker, 2005, p. 31). Chronic pain is complex. It differs from acute pain, which usually has a clear origin (e.g. an injury) and decreases during the healing process. In contrast, chronic pain can alter the neurochemicals responsible for pain regulation; the body is not only deceived into feeling pain in the absence of normally painful stimuli, but also has a magnified response to subsequent episodes of pain (Bradley, 2009; Clauw et al., 2011). This magnification makes it difficult for doctors to trace pain backwards to its source (Barker, 2005). However, researchers have been examining possible explanations for why people with FM experience wind-up.

Neurobiological studies have found irregularities in neurotransmitters that affect pain perception, such as substance P, serotonin, and dopamine (Peterson, 2007). Substance P is a neurotransmitter secreted by neurons in the spinal cord that transmits pain impulses to the brain. Some studies have found that people with FM have elevated levels of substance P, leading to the amplification of pain (Vaeroy, Helle, Forre, Kass, & Terenius, 1988). While substance P sends pain messages to the brain, the neurotransmitter serotonin regulates these messages (Barker, 2005). Studies have found that people with FM have low levels of serotonin (Bradley, 2009). Similar to elevations in substance P, low levels of serotonin can contribute to the heightened experience of pain (Peterson, 2007). Recent studies have also found that people with FM have low levels of dopamine, a neurotransmitter that not only plays a role in pain perception, but also impacts memory, concentration, and mood. Interestingly, impaired cognition (often called *fibro fog*) and low mood are all symptoms of FM (Schweinhardt, Sauro, & Bushnell, 2008).

The evidence of neurotransmitter irregularities has been reinforced by the results of brain imaging tests (Clauw et al., 2011; Goldenberg, 1999; Larson & Kovacs, 2001). For example, studies have used technologies, such as single-photon emission computerized tomography (SPECT) and positron emission tomography (PET), to compare women with FM to healthy controls. These studies revealed that women with FM had lower blood flow to the brain region responsible for pain perception (Mountz, et al., 1995; Schweinhardt et al., 2008). Other studies have shown that people with FM experienced changes in their brain anatomy, such as an annual loss of gray matter (Kuchinad et al., 2007; Schmidt-Wilcke et al., 2007). This gray matter atrophy could be associated with certain FM symptoms, such as difficulties with cognition and pain regulation (Schweinhardt et al., 2008).

In addition to neurotransmitter irregularities, studies have found dysfunction in part of the neuroendocrine system called the hypothalamic-pituitary-adrenal (HPA) axis (Crofford et al., 1994; Griep, Boersma, & de Kloet 1993). The HPA axis impacts people's abilities to respond and adapt to stress (Barker, 2005). Interestingly, research studies have reported that many people with FM have high levels of physiological and psychological stress, as well as difficulty managing the stresses of daily life (Staud, 2004). These high levels of stress contribute to hyperactivity in the HPA axis (Bradley, 2009). They also lead to alterations both in the autonomic nervous system (e.g. blood pressure) and in neurohormones, which impact pain perception (e.g. cortisol and growth hormone) (Crofford, 2007; Goldenberg, 1999; Larson & Kovacs, 2001; Peterson, 2007).

Central sensitivity.

The findings from these neurobiological studies have prompted some researchers to theorize that FM is an organic disorder of sensory processing, *a central sensitivity syndrome*

(Barker, 2005). This theory conceptualizes FM as a constellation of pain and sensory symptoms, including light and noise sensitivities (Yunus, 1984; Yunus, 2001). In addition, this theory posits that FM overlaps with other contested conditions, which involve sensory sensitivity, such as migraine headaches, chronic fatigue syndrome, irritable bowel syndrome, and multiple chemical sensitivity syndromes (Yunus, 2001).

Critiques.

Critics have discussed the weaknesses and limitations of these neurobiological studies. First, irregularities in neurotransmitters and neurohormones are not specific to FM (Peterson, 1997). For example, people with other chronic pain conditions have elevated levels of substance P, as well as alterations in their brains' blood flow (Goldenberg, 1999). Similarly, people with psychiatric disorders and histories of childhood abuse have also displayed HPA dysfunction (Abeles et al., 2007; Winfield, 2000; Zimmerman & Choi-Kain, 2009). Second, it is unclear whether neuroendocrine and neurotransmitter abnormalities are a cause or consequence of FM (Adler, Mansfredsdottir, & Creskoff, 2002; Peterson, 2007). For example, low serotonin levels can contribute to depression, a symptom of FM (Peterson, 2007). However, studies have not determined whether people with FM experience depression solely because of neurotransmitter abnormalities or because chronic pain impacts their daily functioning, relationships, and identities (Peterson, 2007). Third, studies that compared people with FM to "healthy controls" were methodologically flawed; these studies ignored people who existed between the two poles of health and illness, such as those who experienced pain, but did not have an FM diagnosis. If findings from studies that matched people with FM to healthy controls were eliminated, then imaging studies would probably capture a "continuum of results," and therefore appear "less convincing" (Wolfe, 2009, p. 10). Finally, although studies have displayed correlations between

neurobiological abnormalities and FM, correlation does not equal causation. As such, biomedical research has been unable to prove that FM is an organic disease (Wolfe, 2009).

Spectrum disorders.

In comparison to researchers' theory of central sensitization, others have conceptualized FM as a spectrum disorder. However, this is where the similarities end. Researchers who focus on a psychiatric etiology have argued that FM exists on a continuum with depression and other psychiatric disorders. These disorders have been termed affective spectrum disorders (Bradley, 2009; Hudson & Pope, 1989), stress-related somatic syndromes (Crofford, 2007), depression spectrum disorders (Raphael, Janal, Nayak, Schwartz, & Gallagher, 2004), and functional somatic syndromes (Winfield, 2000). By grouping FM with psychiatric disorders, doubt is raised about FM's legitimacy as a biomedical entity.

Psychiatric co-morbidities.

This doubt has been reinforced by research efforts to uncover a relationship between FM and mental illness. For example, some studies have found high rates of co-morbidity among FM and psychiatric disorders, especially depression and anxiety (Arnold, Crofford, Martin, Young, & Sharma, 2007; Epstein et al., 1999; Henningsen, Zimmermann, & Sattel, 2003; Thieme, Turk, & Flor, 2004). In addition, American and Israeli studies have shown that over 50% of people with FM have post traumatic stress disorder (PTSD) (Cohen et al., 2002; Sherman, Turk & Okifuji, 2000). Studies have also compared rates of co-morbidity in different settings. For instance, a Spanish study found the people with FM had similar rates of psychiatric co-morbidity in both primary healthcare and tertiary care settings (Boyer, Mira, Calatayud, Lopez-Roig, & Cantero, 2009). In comparison, North American studies conducted in tertiary care settings

(Epstein et al., 1999) reported higher rates of co-morbidity than studies conducted in the general population (White, Neilson, Harth, Ostbye & Speechley 2002).

Critique.

This body of psychiatric literature has been critiqued. First, studies have been unable to clarify whether: (a) life stressors predispose people to both FM and psychiatric disorders, (b) psychiatric disorders develop as a consequence of living with a chronic condition, or (c) depression and anxiety are symptoms of FM (Epstein et al., 1999; Staud, 2004). Second, it remains unclear whether psychiatric disorders are intrinsic to FM or whether they are prevalent in people who display help-seeking behaviours (Winfield, 2000). Third, the variation in co-morbidity rates between tertiary care clinic and community samples may be a result of differences in geography, access to healthcare, and/or symptom severity (Wolfe et al., 1995). For example, people who have attended tertiary care clinics may be more ill than those who have not sought specialized care. Fourth, high rates of co-morbidity could possibly reflect methodological flaws (Barker, 2005). For example, many studies have used inventories, such as the Minnesota Multiphasic Personality Inventory and the Basic Personality Inventory. These inventories rely on positive responses to symptoms, such as pain, anxiety, and sleep disturbances, in order to identify people with psychiatric disorders (Barker, 2005). However, because people with FM have many of these symptoms, their answers could be false-positives. Consequently, these tests results could incorrectly suggest that people with chronic pain also have psychiatric disorders (Powers, 1993, p. 97).

Environmental stressors.

In addition to the psychiatric literature, there is a growing body of literature that conceptualizes FM as both an organic and a psychosomatic illness in which genetics interconnect

with environmental triggers (Winfield, 2000). For example, researchers have examined genetic risk factors by studying the families of people with FM (Arnold et al., 2004; Hudson, Arnold, Keck, Auchenbach, & Pope 2004; Raphael et al., 2004). These family studies have found that people with FM are more likely than healthy controls to have relatives with either FM or psychiatric disorders, such as depression (Hudson et al., 2004; Arnold et al., 2004). These findings suggest that FM and psychiatric disorders may share common genes. Furthermore, these findings indicate that people may have a genetic predisposition to FM. In other words, people have dormant FM genes, which are later activated and modulated by environmental stressors, such as infections and trauma (Bradley, 2009; Staud, 2004). These environmental stressors then alter people's physiology, including their HPA axis, autonomic nervous system, and brain chemistry (e.g. areas for pain and emotional regulation) (Bradley, 2009; Crofford, 2007).

The theory of environmental stress has led to the hypothesis that different forms of trauma are risk factors in the development of FM (Staud, 2004). For example, a recent study, using data from the 2005 Canadian Community Health Survey (CCHS), found a significant relationship between childhood physical abuse and FM (Fuller-Thomson, Sulman, Brennenstuhl, & Merchant, 2011). In comparison, a study found an association between an FM diagnosis and a history of sexual abuse and physical abuse. However, FM was not associated with a history of emotional abuse, life threatening stress, or major life stress (Haviland, Morton, Oda, & Fraser, 2010). In addition to traumas resulting from physical and sexual abuse, studies have shown a relationship between physical trauma, such as injuries sustained from motor vehicle accidents (MVA), and the onset of FM (Buskila & Neumann, 2002; Tishler, Levy, Masiakov, Bar-Chaim, & Amit-Vazina, 2006; White, Carette, Harth, & Teasell, 2000). For example, one study found

that victims of MVAs were more likely to develop FM than those who caused the accidents (Clauw & Crofford, 2003).

Critique.

These trauma studies have several limitations. First, it has been argued that the findings from MVA studies are supposedly "congruent with animal studies showing that the strongest physiological responses are triggered by events that are accompanied by a lack of control or support, and thus viewed or perceived as inescapable or unavoidable" (Clauw & Crofford, 2003, p. 690). The flaw in this argument is that people are assumed to be passive and vulnerable victims who succumb to their injuries, thereby becoming neurochemically altered. However, people are resilient: they can recover from injuries by creating new neural pathways (Clarke, 2012, p. 215). Second, trauma studies were unable to prove that traumas caused FM. Third, trauma is not specific to FM; it is experienced by people with other illnesses. However, the link between trauma and illness is usually only made when the illness is contested and of unknown origin (M. Parlor, personal communication, July 4, 2011). Fourth, because people tend to underreport abuse, the extent of trauma and its relationship to illness remains unknown (Fuller-Thomson et al., 2011).

Attitudes and behaviours.

In addition to past traumas, studies have examined the ways in which people's present feelings, attitudes, and behaviours have impacted their ability to cope with FM. One author theorized that:

> Generally, pain has two emotional components, including the unpleasantness of the sensation (primary pain affect) and negative feelings such as depression, anger, and fear (secondary pain affect). This relationship of emotions with pain is bidirectional because

modulation of negative feelings can powerfully alter the pain experience" (Crofford, 2007, p. 306).

The interconnection between negative feelings and the experience of pain was explored in an Australian study. This study found that chiropractic patients with FM felt more distressed and had a lower sense of coherence (meaning the ability to see life as predictable, organized, and manageable) than chiropractic patients without FM (Jamison, 1999). In comparison, a Portuguese study, which examined the interconnection of FM and adult attachment patterns, found that people with FM coped with chronic stress by worrying (Oliveira & Costa, 2009). The authors suggested that people who worry too much have a tendency to be hyper-vigilant about themselves and others, which in turn, leads to an overreaction about physical symptoms.

These behavioural studies acknowledged individual variations in coping patterns. However, they did not address the role that early childhood experiences and traumas played in shaping adult behaviours and attitudes. Consequently, this focus on the adult self devoid of history implicitly pathologizes people with FM.

Summary.

In summary, physiologically-focused researchers have examined multiple theories about FM's etiology, including virology and muscle metabolism, sleep patterns and neurobiology. In comparison, mind-focused researchers have examined the prevalence of psychiatric co-morbidities, the relationship between genes and environmental stressors, the role of past traumas, and the coping patterns of people with FM. Unfortunately, after four decades of debate, both sides have found variables that may contribute to FM, but they cannot prove causation.

Shifting Research Directions.

Although biomedical researchers have continued to examine theories of causation, the inability to uncover FM's etiology has led some researchers to shift their focus to the study of treatments (Peterson, 2007). On one hand, this shift provokes questions about whether the search for FM's etiology has become futile. On the other hand, this shift represents the increasing power of pharmaceutical companies to fund and therefore influence the direction of research (Moynihan, Heath, & Henry, 2002). It is not a coincidence that most of the treatment literature has focused on pharmacology, examining the efficacy of medications, such as antidepressants, muscle relaxants, and analgesics.

Despite this pharmacological focus, many studies have argued that treatments should, in addition to medications, include multi-faceted and individually tailored therapies (Baker & Barkhuizen, 2005; Huynh, Yanni, & Morgan, 2008; Patkar, Bilal, & Masand, 2003). For example, some studies have evaluated non-pharmacological interventions, including education, cognitive behavioural therapy, nutrition, exercise, massage, acupuncture, hypnotherapy, and biofeedback (Goldenberg, Burckhardt, & Crofford, 2004; Peterson, 2007). Several studies have also recommended a holistic approach, incorporating naturopathy and spiritual practices (Lind, Lafferty, Tyree, Diehr, & Grebowski, 2007; Nicassio, Schuman, Kim, Cordova, & Weisman, 1997). Although some studies have found significant improvements with drug therapies (Krypel, 2009) and non-pharmacological treatments (Rossy, et al., 1999), other studies have reported that the efficacy of treatments is minimal (Glombiewski et al., 2010). For example, in a meta-analysis of anti-depressant medication, only one in four people with FM experienced symptom improvement (O'Malley et al., 2000).

The Canadian National Fibromyalgia Guideline Advisory Panel recommends that doctors treat FM through a combination of pharmacological and non-pharmacological interventions, including patient education, exercise, complementary and alternative medicine (CAM), and cognitive behavioral therapy (Fitzcharles et al., 2012). However, in a recent Ontario study about the healthcare needs of people with FM and other chronic conditions, participants reported that treatments were either ineffective for symptom management and alleviation or unsustainable due to cost (Burstyn, 2013).

These mixed results of treatment studies can be attributed to FM's chronic nature, as well as to individual variation in the severity of the condition. Consequently, many authors have discussed that a realistic goal of treatment is the reduction rather than the elimination of symptoms (Fitzcharles, Costa & Poyha, 2003; Noller and Sprott 2003; Wolfe et al., 1997).

The shifting role of rheumatology.

As previously described, over the past few decades, rheumatologists assumed responsibility for the assessment and treatment of FM. However, a recent survey found that 71% of Ontario rheumatologists believed that they no longer should provide care to patients with FM. In fact, 89% of Ontario rheumatologists believed that the care of patients with FM should be transferred to family doctors (Ghazan-Shahi, Towheed, & Hopman, 2012). The argument behind this transfer of care is that FM does not fit within rheumatology's jurisdiction because it is no longer considered a musculoskeletal disorder. Instead, many researchers and clinicians conceptualize FM as a multi-symptom disorder of the nervous system (Barker, 2005). In comparison, others, including 55% of the surveyed rheumatologists, view FM as a psychosomatic illness. Interestingly (or as might be expected), rheumatologists who considered

FM a physical illness were more likely to believe that they should continue treating patients with FM, as well as to accept new referrals (Ghazan-Shahi et al., 2012).

It is possible that the underlying reason why many rheumatologists no longer want to assume responsibility for FM is because it is a condition that: has an unknown etiology; does not have simple treatments; has multiple symptom involvement; is primarily diagnosed in women; and, has no cure and therefore rarely yields a sense of medical success. Regardless of the reason, rheumatologists are now able to extricate themselves from patients with FM due to the ACR's revised classification criteria. By deleting the tender point exam, the ACR has pushed FM outside of rheumatology's musculoskeletal jurisdiction.

The ACR's revised classification criteria coupled with the findings of the Ontario rheumatology survey provokes questions about who could and should deliver healthcare services to the FM patient population. If rheumatologists relinquish responsibility for the provision of healthcare services, then which medical speciality would be best suited to care for patients with FM? By default, the responsibility for service delivery has fallen on family physicians. Although I agree family physicians should have a major role in FM care, it is unfair to both family physicians and patients to leave family physicians with unsupported responsibility. Family physicians require specialists to conduct research, provide knowledge transfer, and deal with complex cases. Regardless of which medical speciality eventually assumes responsibility for FM, this condition is currently an orphan within the Canadian healthcare system.

From Quantitative to Qualitative Literature

Biomedical Constructions of FM and Patient-Provider Experiences

The synthesis of the science literature reported above has highlighted that FM is a biomedically-constructed condition. Since the early 1900s, the construct of FM has undergone

shifts in terms of terminology, research directions, classification criteria, and support from doctors. These biomedical shifts trickle into the realm of healthcare, influencing how healthcare providers and patients with FM understand this condition and relate to one another. In turn, these interactions shape the experiences of what it is like to be a patient with FM (Hazemeijer & Rasker, 2002).

The majority of literature on FM is biomedical. However, there is a small but slowly growing body of qualitative literature on FM, in general, and on the experiences of people living with FM, in particular. There are also a few studies about the perspectives of healthcare providers. The majority of these studies are North American and Scandinavian. I wonder if the dearth of qualitative literature reflects the biomedical illegitimacy of FM. In other words, perhaps it is difficult for qualitative researchers to explore the meaning of a condition that is attached to so many conflicting and uncertain meanings. Regardless of the reason, it is important to explore the experiences of both people living with FM and healthcare providers.

In a metasynthesis of qualitative studies, Sim and Madden (2008) found four themes in the literature about the experiences of people living with FM. Qualitative studies reported findings about people's experiences of symptoms, quests for diagnosis, desires for legitimacy, and strategies to cope with FM (Sim & Madden, 2008). In my own review of the qualitative literature about FM experience, I observed similar thematic trends. In this section, I have synthesized the literature related to people's healthcare experiences, as this is the focus of the dissertation study. However, I have also integrated themes of loss and coping because the experience of FM permeates into all aspects of social life and identity. Furthermore, I have reviewed studies about healthcare providers' experiences of diagnosing and treating patients with FM.

Patients' Experiences of Healthcare, Loss, and Adaptation

Experiences of healthcare as a journey.

Within FM qualitative research studies, participants' illness experiences have been conceptualized as a journey along a continuum (Raymond & Brown, 2000) and as a series of transitions (Soderberg & Lundman, 2001). These studies describe participants' healthcare journeys as involving a beginning, middle, and an end. In many studies, for example, participants' described experiencing biographical disruptions, as the insidious onset of symptoms interrupted their health, identities, and social lives, therefore prompting them to seek medical attention (Kelly & Clifford, 1997; Raymond & Brown, 2000; Sim & Madden, 2008). Many participants reported feeling like "guinea pigs" having to undergo numerous tests and repeating their stories to multiple healthcare providers (Paulson et al., 2002). After lengthy diagnostic journeys, however, participants were eventually diagnosed with FM, which resulted in experiences of relief and legitimation (Barker, 2002; Kelly & Clifford, 1997; Raymond & Brown, 2000; Sim & Madden, 2008). Many studies achieved narrative closure by exploring how participants learned to accept their biographical disruptions (Barker, 2002; Kelly & Clifford, 1997; Raymond & Brown, 2000; Sim & Madden, 2008).

Experiences of diagnosis and treatment.

Some studies have found that participants felt legitimated through the act of being diagnosed with FM. For example, a study examined how patients with rheumatic diseases including FM experienced their healthcare encounters. This study found that participants felt that obtaining "a diagnosis implied *being believed*" (Haugli, Strand, & Finset, 2004, p. 171). The authors explained that the experience of "*being believed*" meant that healthcare providers believed that patients' conditions were physical rather than psychosomatic. In addition, a study

reported that participants adopted biomedical explanations of FM in order to understand why they became ill (Madden & Sim, 2006). As Barker (2002) explained, the FM diagnosis "offers a way of 'remaking' the world by creating an overarching framework that gives order and meaning to past, present, and future symptomology... The diagnostic narrative of FMS [fibromyalgia syndrome] functions as a narrative of selfhood" (p. 289).

In comparison to studies that described diagnostic relief, other studies have reported that the FM diagnosis neither leads to clarity nor understanding. For example, a study, which explored women's experiences of being diagnosed with FM, found that participants spent years suffering from unexplained symptoms and searching for a diagnosis (Undeland & Malterud, 2007). After finally being diagnosed, some participants experienced relief, as the diagnostic label of FM provided legitimation. However, participants eventually realized that the diagnosis did not lead to finding effective treatments or emotional support. Instead, they experienced stigma and isolation (Undeland & Malterud, 2007). Other studies have also found that participants reported feeling powerless, as diagnosis did not lead to a sense of closure (Raheim & Haland, 2006; Sim & Madden, 2008).

Studies have found that participants struggle not only with diagnosis, but also with the treatment process. In some studies, for example, participants expressed uncertainty about their prognosis, questioned the efficacy of treatments, and felt that healthcare providers did not provide enough support (Madden & Sim, 2006). A recent study found that participants were viewed by healthcare providers as malingerers and hypochondriacs because FM was an invisible condition with an unknown origin. These participants also reported being ignored by healthcare providers because all of their test results were negative (Juuso, Skär, Olsson, & Söderberg, 2014). The theme of being ignored by healthcare providers is echoed in other studies. For

example, a study found that participants reported informing healthcare providers of new symptoms, but the providers did not assess for comorbidities and instead assumed the symptoms were part of the FM, thereby giving the condition "master status" (Madden & Sim, 2006).

Experiences of loss.

Studies have found that participants struggled with the stigma of the healthcare system, as well as with experiences of loss. Some studies, for instance, have examined how debilitating symptoms impacted participants' senses of self (Cudney, Butler, Weinert, & Sullivan, 2002). Studies have found that because of FM, participants did not feel whole and viewed their bodies as obstructions (Paulson et al., 2002), burdens (Soderberg et al., 2002), and prisons (Raheim & Haland, 2006). One study reported that participants experienced a "never-ending struggle with an unwilling body" (Raheim & Haland, 2006, p. 755). These participants were "at the will of the treacherous body," a body which moved slowly, was always in pain, and did not allow activities of daily living to be completed (Raheim & Haland, 2006, p. 747). These participants felt that their dignity was threatened, as they were stuck in an "existential breakdown" after years of living in chronic pain (Raheim & Haland, 2006, p. 756). Other participants struggled "to escape the treacherous body," but found that pre-illness coping strategies were no longer effective for managing life. As a result, they were overwhelmed by pain, guilt, ambivalence, and despair (Raheim & Haland, 2006, p. 749).

In addition to the loss of their pre-illness bodies and identities, studies reported that participants grieved due to changing roles, relationships and careers (Raymond & Brown, 2000; Soderberg & Lundman, 2001; Soderberg et al., 2002). Participants reported experiencing isolation, as the unpredictability of their symptoms made it difficult to plan social activities (Arnold et al., 2008 Asbring, 2001; Crooks, 2007; Raymond & Brown, 2000). In other words,

these participants moved from active to passive lives (Asbring, 2001), as FM became "the choreographer of activity and relationships" (Soderberg & Lundman, 2001, p. 625). Another study found that participants experienced loss of support from their families who expected them to engage in the same activities they enjoyed together prior to the onset of illness (Juuso et al., 2014). This study also found that participants lost support in the workforce; because of the invisibility of FM, participants were labeled as lazy when they required workplace modifications (Juuso et al., 2014).

Experiences of coping and personal growth.

Despite these struggles and losses, some studies have found that participants learned how to adapt to living with FM. For example, one study described how participants utilized self-management strategies to manage their symptoms and their lives, thereby experiencing a sense of self-efficacy (Kengen Traska, Rutledge, Mouttapa, Weiss, & Aquino, 2011). Other studies have reported that participants' process of developing coping skills involved: learning to understand FM; adopting accommodating behaviours; building support systems and positive relationships with healthcare providers; expressing loss about previous abilities; and, deciding whether to continue working or to receive disability pensions (Raymond & Brown, 2000; Schaefer, 1997; Schaefer, 2005).

In addition to coping skills, some studies have found that participants learned to accept the loss of control over their lives (Soderberg & Lundman, 2001). The process of acceptance involved participants' realizing that biographical disruptions were partial; not all aspects of their lives and identities had changed (Asbring, 2001). Because participants' activities were restricted by pain and fatigue, they had time to reflect upon, re-evaluate, and change their lives and relationships, obligations, and priorities (Asbring, 2001). Consequently, these changes were

"illness gains," meaning that participants increased their self-respect and, at times, developed more favourable identities (Asbring, 2001).

While some studies discussed individual strategies for growth and FM management, others have examined adaptation to illness as a collective quest. For example, a study of an on-line group for FM sufferers found that participants shared philosophical advice and practical strategies in order to obtain control over their illness; the on-line forum also helped participants' foster new relationships (Cudney et al., 2002).

Experiences of Healthcare Providers

There is a very small body of qualitative literature that explores the perspectives of healthcare providers. Several studies have: (a) compared the experiences of patients with FM and those of healthcare providers (Briones-Vozmediano, Vives-Cases, Ronda-Pérez, & Gil-González, 2013; Hayes et al., 2010); and (b) solely examined the perspectives of healthcare providers treating patients with FM, as well as other chronic conditions (May et al., 2004; Wainright, Calnan, O'Neil, Winterbottom, Watkins, 2006). These studies have reported similar findings about providers' beliefs about FM, attitudes towards patients, and experiences diagnosing and treating FM. In a recent study, for example, researchers interviewed healthcare providers and patients with FM about patient-provider relationships, diagnostic procedures, and management of the condition (Briones-Vozmediano et al., 2013). This study found that both patients and providers experienced frustration with the delayed process of FM diagnosis and lack of effective treatments. Patients reported that they required more support from providers, while providers reported helplessness and uncertainty around how to best support patients. In comparison, a Canadian study, utilizing a mixed-methods approach, examined the experiences of family doctors, specialists, and patients with FM. This study's objective was to understand the

dynamics of patient-provider relationships as well as the underlying attitudes within these relationships (Hayes et al., 2010). This study found that some doctors and specialists viewed patients with FM as malingerers and either did not believe FM could be diagnosed or they lacked the necessary diagnostic skills.

Some studies found that healthcare providers could establish relationships with patients even if they questioned the legitimacy of patients' diagnoses. For example, a study about medically unexplained arm pain found that doctors were willing to strategically negotiate and bestow diagnoses (Wainwright et al, 2006). Doctors diagnosed FM as "a useful means of managing the doctor – patient relationship, which avoids invalidating the patient's illness claim and allows the consultation to focus on ameliorative treatment rather than a continual search for an elusive diagnosis" (Wainwright et al., 2006, p. 83). In comparison, a qualitative study utilized the method of comparative analysis to explore how family doctors conceptualized chronic illnesses, such as menorrhagia, depression, low back pain, and medically unexplained symptoms (May et al., 2004). The authors proposed that: "When medical and lay models of symptoms are congruent, doctors' evaluations of the patient are less problematic, even though the patient's motivation and legitimacy of symptoms may be in question" (May et al., 2004, p. 152). In other words, doctors were more likely to have smoother relationships with patients when both parties shared similar interpretations about the origins of the illness.

Chapter Summary

FM is a postmodern condition, as it exemplifies the Foucauldian theoretical tenet that medicine is situated within culture and history. The social history of the shifting biomedical constructions of FM reinforces the argument that the condition remains as precarious today as it was a hundred years ago. This precariousness is reflected in both the biomedical and the social

science literature on FM. The qualitative social science literature reveals that people with FM experience complex healthcare journeys and multiple losses. The literature also explores how despite struggles and stigma people with FM learn strategies to cope with their conditions and changing roles and relationships. Furthermore, the qualitative literature examines how both patients with FM and healthcare providers experience FM as an illegitimate condition. In sum, a synthesis of the literature has illuminated how biomedical uncertainty has contributed to the illegitimacy of FM, as well as to the marginalization of people suffering from this unsuccessfully medicalized condition.

CHAPTER FOUR – RESEARCH METHODOLOGY

Figure 5: Brian's body map.

I open this chapter with Brian's artwork to illuminate the beauty of body-map storytelling, an accessible ABR methodology. Body maps can be created by men and women of all ages and backgrounds. This methodology does not require formal art training and can be adapted to meet the needs of participants living with pain and mobility issues; all that is required is a paintbrush and a passion to share stories. However, there is methodological artistry involved in order to: transform abstract inquiries about human experience into concrete art activities; foster a safe environment where participants can verbally and visually express themselves; and, analyze the data in a manner that conveys the richness of participants' artistic voices. Given these complexities, the purpose of this chapter is to provide an in-depth description of how and why I selected the research methodology of body-map storytelling. As such, in this chapter, I outline this study's research design, including the procedures for recruitment, methods of data collection, process of data analysis, and strategies for knowledge translation. I also share some of the lessons that I have learned from utilizing this methodology.

Research Question

This study was guided by the research question: "How do men and women who have a diagnosis of FM experience interactions with healthcare providers?" This critical research question enabled deep exploration of participants' perspectives of both positive and negative aspects of their care experiences. It was important to uncover both the positive and negative aspects of care because data about helpful and unhelpful experiences will be shared with stakeholders to promote the innovative design and delivery of non-stigmatizing, patient-centred healthcare services.

Incorporating Systems of Embodied Differences

The research question guided inquiry about the experiences of both men and women because although FM is primarily diagnosed in women, it also impacts men, possibly more men than we realize (Paulson, Danielson, & Norberg, 1999; Paulson, Danielson, & Soderberg, 2002; Paulson, Norberg, & Danielson, 2002). However, a limited amount of qualitative research about men with FM has been conducted (Paulson et al., 1999; Paulson et al., 2002). Out of 18 qualitative research studies that examined the subjective experiences of people with FM, 12 studies interviewed women; only three studies interviewed men and three studies interviewed both men and women (although there was only one man in each of these samples). Given the lack of studies about men, this study's research question allowed comparison of the ways in which men and women's interactions with healthcare providers were shaped by gender. This question enabled a comparative exploration not only across gender but also within the gendered categories of men and women.

As described in the first chapter, I realized through the process of data collection and analysis that the research question focused on gender and did not inquire about the ways in which gender intersected within a system of embodied differences. Although I did not change the research question, I did revise the study's theoretical framework and data analysis plan to explore the system of embodied differences, including gender, age, race, culture, and class.

A Qualitative Research Approach

The Rationale for Collecting Data via Focus Groups

This study's research question was open-ended, exploratory and focused on people's experiences, and therefore required a qualitative approach. I collected data via in-depth interviews and focus group sessions. Focus groups, a method of accessing data through the

process of participant interaction (Asbury, 1995; Webb & Kevern, 2001), were selected for five reasons. First, focus groups helped to fill a methodological gap in the literature. Qualitative studies on FM have primarily collected data from interviews with individuals (Sim & Madden, 2008). For example, I found only two studies that collected data from people living with FM via focus groups (Arnold et al., 2008; Barker, 2002), two studies that collected data from on-line support groups (Barker, 2008; Cudney et al., 2002), and one study that collected data from narrative group therapy sessions (Kelly & Clifford, 1997).

Second, this method was an appropriate fit with the study's focus and research question. In general, focus groups are commonly used to research experiential knowledge, probing "not only what people think but how they think and why they think that way" (Kitzinger, 1995, p. 299). In particular, focus groups are often used to study experiences about health, illnesses, diseases, and healthcare services (Kitzinger, 1995).

Third, focus groups can uncover in-depth and "unanticipated" information (Lukens, Thorning & Lohrer, 2004). The focus group literature describes how participants may share rich information because they feel uninhibited engaging in group discussions, which spark further thoughts and ideas. Through these discussions, people can "explore and clarify their views in ways that would be less easily accessible in a one to one interview" (Kitzinger, 1995, p. 299).

Fourth, people with FM experience social isolation because they are often misunderstood by their families and friends and housebound due to pain and decreased mobility (Soderberg et al., 1999). Given this fact, focus groups have the potential to reduce isolation, promote socialization, and increase self-esteem. Focus groups can also promote reflection and learning through collaborative discussions (Lukens et al., 2004). Another therapeutic benefit is that

through conversations, participants can co-construct alternative narratives, which create possibilities and limit oppression.

Finally, focus groups generate critical discussions more often than individual interviews (Kitzinger, 1995). Constructive criticism can break the silence of taboo topics, providing valuable information and suggestions for improving healthcare services.

> A method that facilitates the expression of criticism and the exploration of different types of solutions is invaluable if the aim of research is to improve services. Such a method is especially appropriate when working with particular disempowered patient populations who are often reluctant to give negative feedback or may feel that any problems result from their own inadequacies (Kitzinger, 1995, p. 300).

Blended Methodologies

In this study, focus groups were structured by a unique approach to data collection. I collected data by blending methods of constructivist grounded theory with a participatory component, an ABR project called body-map storytelling. In the focus group sessions, I intertwined body-map storytelling with discussion, while using constructivist grounded theory to code and analyze the data. There were three reasons for blending these approaches. First, people with FM are a marginalized population, and ABR is utilized to empower marginalized communities. However, ABR's credibility has been challenged (Haines-Saah & Oliffe, 2012). Combining ABR with grounded theory, an established and accepted methodology, increased this study's credibility. Second, both ABR and grounded theory are widely used to explore subjective experience (Charmaz, 2006; Haines-Saah & Oliffe, 2012), and therefore mesh with this study's focus and research question. Third, both ABR and grounded theory are compatible with focus groups. ABR is usually carried out in groups because participants engage in communal projects

(Cornwall, 1992). In comparison, grounded theory allows researchers to deeply probe a topic in a group environment (Starks & Brown Trinidad, 2007).

Constructivist grounded theory.

Grounded theory, which is rooted in symbolic interactionism, has multiple variations (Starks & Brown Trinidad, 2007). Consequently, this methodology offers paradigmatic flexibility, as it is not wedded to a single epistemology (Charmaz, 2006). For the purpose of this study, the methodology with the best epistemological fit was Charmaz's constructivist (also referred to as social constructionist) grounded theory. This methodology complemented the study's theoretical framework, meshing with both critical inquiry (Charmaz, 1990, 2006) and feminism (Dominelli, Stega, Callahan & Rutman, 2005). Within a critical feminist paradigm, grounded theory links the micro to the macro, focusing on the relationship between individuals and their larger social contexts (Dominelli et al., 2005). For example, grounded theory can uncover how individual gender roles have socioeconomic implications (Austen, Jefferson, & Thein, 2003). In this study, grounded theory helped to expose how some participants felt that the process of interacting with healthcare providers was an experience intricately affected by their gender and other systems of embodied differences. Moreover, grounded theory supported the framing of FM as a social construction, which was co-created through the interaction of patients, providers, and healthcare institutions.

Epistemologically, constructivist grounded theory carries specific beliefs about the nature of reality. Namely, this methodology assumes that: (a) individuals/participants construct their realities (e.g. ideas, beliefs, and emotions); and (b) these emergent realities are multiple, "fundamentally shaped by social interaction", and undergo further construction through the researcher's analytic process (Charmaz, 1990, p. 1161). Through this process, the researcher's

and participants' standpoints both influence and are influenced by the research environment. They co-create data through their "shared experiences and relationships" (Charmaz, 2006, p. 130). The researcher then analyzes the co-created data, which becomes an interpretation of reality.

Because subjectivity shapes research, it is crucial for researchers to be actively self-aware throughout the process of data collection and analysis (Charmaz, 1990). Taking an "active stance" of self-awareness, I used constructivist grounded theory in order to uncover new themes and concepts (Creswell, 1998). I had the freedom to be open to the data, rather than being guided by preconceived categories. At the same time, I was aware of the ways in which my theoretical framework (e.g. how power/knowledge operates in systems, etc.) and values (e.g. power, social justice, equity, etc.) shaped my interpretation of the data.

Constructivist grounded theory is an inductive approach used to explore social interactions and processes (Charmaz, 2006), as well as experiential knowledge (Wee & Paterson, 2009) and health related issues. For example, Charmaz (1990) utilized this methodology to study the experiences of people living with chronic illnesses.

Constructivist grounded theory is a compatible methodology for collecting data via focus groups (Webb & Kevern, 2001). In the field of healthcare, for example, numerous studies have used grounded theory to collect and analyze focus group data. These studies have explored the experiences of individuals who have: relatives with mental illness (Lukens et al., 2004; Stjernsward & Ostman, 2008); sought treatment for overactive bladder symptoms (Anger et al., 2011); and, returned to work after a period of sick leave (Haugstvedt, Hallberg, Graff-Iverson, Sorenson & Haugli, 2011).

Constructivist grounded theory not only fit with this study's purpose, paradigm, and research question, but also with its intended application. Specifically, I will translate knowledge about the research findings to healthcare providers in order to raise awareness, reduce stigma, and promote social change. These goals are echoed by Charmaz (1990):

> Grounded theory analyses can then provide physicians with alternative understandings of patients' beliefs and actions than those readily available in clinical settings. Subsequently, physicians may use these understandings to improve communications with patients and to act on problems which patients define (p. 1161).

ABR methods for exploring verbal and visual narratives.

Like grounded theory, ABR is rooted in experience (Shusterman, 2010). However, ABR offers an alternative mode of communicating experiences, given that verbal language cannot always capture the complexity of feelings and thoughts (Baerg, 2003; Eisner, 2006). In 1993, the first ABR program was established at Stanford University in order to address the need for "methodological pluralism" (Eisner, 2006, p. 11). Unfortunately, academia has tended to reinforce the dichotomy of art and science; art is labelled as a process of feeling whereas science is defined as a method of reason (Eisner, 2006; O'Donoghue, 2009; Ward, 2011). Consequently, many academic institutions consider ABR to be a contradiction and an "alternative" method. Despite these critiques, ABR is slowly growing in popularity.

Art "opens up a space for us to think about arts-based research as a process (coming to know) and as a product (representation of knowing and providing opportunities for others to come to know)" (O'Donoghue, 2009, p. 357). ABR promotes research participants to narrate their lives through visual methods, such as poetry and paintings, film and photography. In the social sciences, for example, photography has evolved from a colonial art form (whereby the

researcher would take pictures of passive subjects) to a post-colonial, community-based, feminist method, which empowers marginalized people and privileges their experiences (Haines-Saah & Oliffe, 2012).

ABR: Body-Map Storytelling

The experience of being a patient is a form of body politics. In other words, the body is marked and molded through the process of diagnosis and treatment, becoming a site of struggle and stigma (see Foucault, 1989). The body requires an outlet to express the experience of the politicized self. However, because people with FM are marginalized, sharing bodily experiences through words can be painful. I offered participants an ABR project as an alternative means of communication, an opportunity to combine both verbal and non-verbal forms of expression.

In this study, participants engaged in the process of body-map storytelling. Body maps are life size drawings, which depict people's inner-worlds within their social contexts (MacGregor, 2009). Body maps are cathartic outlets, narratives, tools for anti-oppression, representations of the self in context, and life-size portraits of courage (CATIE, 2006). Body mapping is a multifaceted tool, which can be used for a wide range of purposes, including art and narrative therapy, advocacy, team building, treatment information and support, and participatory qualitative research (Solomon, 2006).

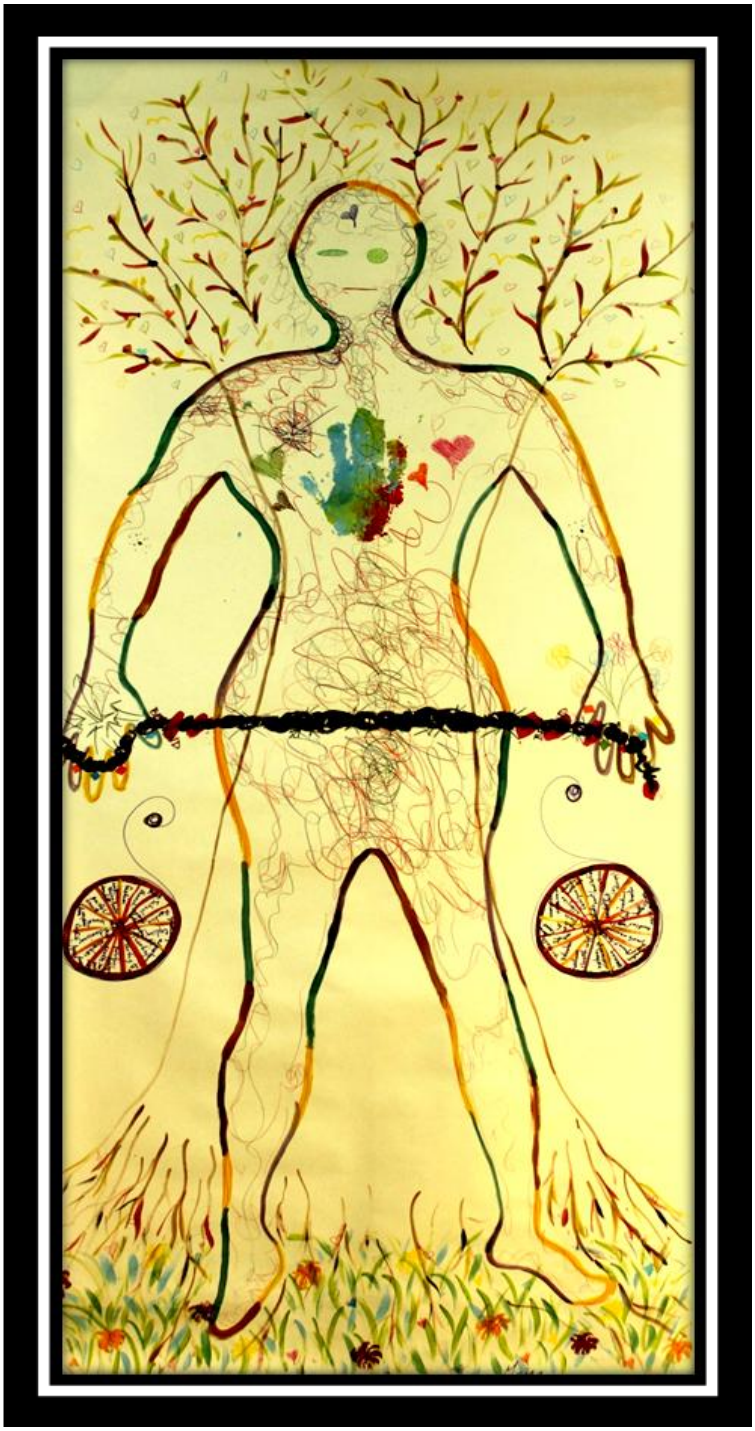


Figure 6: Moira explained, “I just found this whole process [of body-map storytelling] very organic and that came through in doing this.”

Unfortunately, the literature on body mapping is limited. I found one article that summarized the history of body mapping and its possible application to the study of occupation (Hartman, Mandich, Magalhaes & Orchard, 2011). Another article reviewed the ways in which body mapping has been used as an advocacy tool in South Africa (MacGregor, 2009). I also found several articles reporting findings from research studies. For example, a British study used body mapping in conjunction with semi-structured interviews to examine dancers' embodied experiences of injury and pain (Tarr & Thomas, 2011). Furthermore, a study in Zimbabwe used body mapping to probe local women's knowledge about their reproductive health (Cornwall, 1992). A study in the Philippines used body mapping to explore children's perspectives about bodies, health, and illness within the larger context of poverty and inequality (Mitchell, 2006).

The literature describes different forms of body mapping. However, the clearest and most transparent version of body mapping was developed by Jane Solomon and the Regional Psychology Support Initiative (REPPSI) team in order to work with people with HIV and AIDS in East and South Africa (Hartman et al., 2011). Solomon (2006) authored a manual, outlining instructions on how to facilitate body mapping workshops. In this manual, Solomon describes body mapping as a form of storytelling, enabling women with HIV/AIDS to explore their knowledge and experience of disease, as well as their life journeys, through imagery and words. Solomon's (2006) version of body mapping is an intricate and intensive process, which requires over 30 hours of engagement during a five-day workshop. In these workshops, participants first trace their bodies on paper and then engage in 20 exercises, which incorporate drawings with reflections and discussions (T. Smith, personal communication, July 24, 2012).

Solomon's manual was recently adapted by Gastaldo et al. (2012) in order to transform body mapping from an art therapy tool to a research methodology for the purpose of examining

the migration journeys of undocumented workers. Gastaldo et al. (2012) renamed the methodology body-map storytelling to differentiate it from Solomon's art therapy modality. I adapted Gastaldo et al.'s (2012) body-map storytelling in this dissertation study because she published a manual with detailed instructions about how to implement the methodology.

I have blended body-map storytelling into this study because the methodology fits with the study's purpose, research question, and theoretical framework. This methodology is also an innovative tool for exploring the mind-body in context, creating new narrative formats, and promoting social justice.

Methodological and theoretical cohesion.

Body-map storytelling fits with the research question's focus on healthcare experience. Body mapping is a suitable methodology "for gaining access to people's perceptions of their bodies and to the explanatory models which people bring into encounters with health care workers" (Cornwall, 1992, p. 1). In this light, body-map storytelling is a creative way of collecting data about healthcare experiences. This method also addresses the gendered aspect of the research question; participants map how their bodies are not only gendered, but also shaped by embodied systems of differences, including age, class, race, and culture. Furthermore, body-map storytelling has helped fill a methodological gap in the literature; previous qualitative studies about FM have not incorporated ABR into their designs.

Body-map storytelling is compatible with this study's theoretical framework. Namely, body maps are personal constructions/representations of participants' pre-illness identities and current functioning, as well as their shifting roles and relationships with significant others and healthcare providers.

Body-map storytelling fits with focus groups. This methodology works best in groups, as participants are both a source of support and inspiration (Solomon, 2006). Participants produce knowledge about their bodies through dynamic interactions. This relationship between the body and social interaction can be described as the "socialization of science" (MacGregor, 2008, p. 91).

Exploring the mind-body in context.

Body-map storytelling can help participants reflect upon the connection of their minds and bodies, feelings and thoughts, experiences and social interactions. For instance, body-map storytelling can provide participants with a non-verbal method for expressing "experiential states," such as pain, discomfort, and frustration, which may be difficult to verbalize (Mitchell, 2006, p. 341). These feeling states can be illuminated by the freedom of framing the body in personal and meaningful ways. Body-map storytelling rejects framing the body in an impersonal manner (Mitchell, 2006, p. 342) by providing an alternative to standardized medical representations of FM. The standardized FM body, which is frequently depicted in informational material about FM, displays black dots scattered on the front, back, and side of nude female figures in order to represent the location of tender points (Oldfield, 2011).

Body-map storytelling is a holistic method of blending the mind, body, and social context. As previously discussed, debates about FM have revolved around whether this condition is located in the body or the mind. However, body-map storytelling moves beyond the Cartesian dualism of the medical model, thereby addressing this metaphysical split. By blending the mind and body, body-map storytelling can enable participants to express what it was like to live inside a body with FM, as well as how their bodies and sense of self are shaped by interactions within the healthcare system.

Creating new narrative formats.

Body-map storytelling can stimulate insights that may not arise via traditional qualitative approaches. This process entails "a less directive interviewing style" whereby participants' visual descriptions are probed by the researcher (Cornwall, 1992, p. 1), as well as by fellow focus group participants. Through dialogue, participants can reflect upon the context in which the body maps were produced. For example, they can discuss what they felt the researcher expected of them and whether or not they conformed to these expectations (Cornwall, 1992). During this process, ample time is available for reflection in comparison to interviews where participants are expected to answer questions in a relatively quick fashion (Hartman et al., 2011). Furthermore, body-map storytelling can elicit unique and creative insights because this method activates cognitive processes in parts of the brain that are not frequently accessed (Hartman et al., 2011). Through body-map storytelling, participants can formulate "a tangible visual representation of abstract issues in a way that they may have never done before, which can result in new insights or unveil burdens that they were previously unaware of" (Hartman et al., 2011 p. 300).

Body-map storytelling can help people with chronic conditions experience liberation through the process of telling stories (Frank, 1995). Storytelling is a form of self-expression, which can establish people's credibility and validate the legitimacy of their illness (Werner et al., 2004). Such narratives can construct an alternative reality to dominant medical discourses, which instruct people on how to behave as good patients and medicalized bodies (Whitehead, 2006). Alternative narratives express the suffering that mainstream medicine often refuses to hear (Bendelow, 2006; Hyden, 1997).

Body-map storytelling is also a form of societal narratives: socially-shared stories (Murray, 1999). Through societal narratives, individual experiences are transformed into

collective experiences (Hyden, 1997). The process of collectively sharing narratives is therapeutic, especially for people living with chronic and contested conditions (Kelly & Clifford, 1997). Societal narratives can involve a cathartic process of "witnessing" (Frank, 1995). In other words, groups provide forums for participants to publicly share their illness narratives, be heard, have their experiences validated, and repair the losses caused by the biographical disruptions of illness (Bulow, 2004).

Within the FM empirical literature, illness experiences are often structured by a similar narrative format. These narratives begin by describing biographical disruptions, such as the ways in which FM has interrupted research participants' health, identities, and social lives. These narratives achieve closure by exploring how participants have learned to accept their biographical disruptions. The homogeneity of this narrative structure is problematic, concealing diverse narratives of what it is like to live with FM. In comparison, body-map storytelling provides opportunities for alternative narratives to be exposed.

A medium for social justice.

Body-map storytelling can empower a group of people who have been marginalized within the healthcare system. Empowerment is fostered through the process of self-expression and collaboration. Body-map storytelling celebrates embodiment, the integration of "knowing, acting, and being" (Barnacle, 2009, p. 26). Body-map storytelling is both a political and an ironic method, given that people with a contested condition participated in a contested or "alternative" form of research.

Finally, through the process of knowledge translation, body-map storytelling can promote social change, one of the purposes of this study. In the context of FM, healthcare encounters can be stigmatizing. However, body-map storytelling provides a unique vantage point in order to

view problems and approach solutions differently (Mitchell, 2006). Therefore, this method can potentially generate opportunities to brainstorm new ways of improving healthcare interactions. Body-map storytelling also facilitates social change through advocacy; these maps will be shared with FM stakeholders, such as policy makers and practitioners, to raise awareness and decrease stigma about FM.

Research Design

Thus far, I have explained the reasons why I combined body-map storytelling with constructivist grounded theory in focus group sessions. I will now describe the details of this research design.

Recruitment Procedures

In October 2012, I received approval for this study from Wilfrid Laurier University's Research Ethics Board. From January to March 2013, I recruited 49 potential male and female participants for the dissertation study. This recruitment process was time consuming yet enjoyable, involving extensive communication and collaboration with supportive stakeholders and potential participants. This process also led to modifications in the research design due to emergent issues.

I originally proposed to recruit participants from tertiary care settings, which had assessment and treatment programs for people with FM, such as Women's College Hospital's Environmental Health Clinic. Although the providers at the Environmental Health Clinic were eager to assist with recruitment, I was required to submit an ethics application to the hospital's Research Ethics Board, a lengthy process that would delay recruitment. Moreover, as per hospital policy, one of the Clinic doctors had to assume the role of Principal Investigator for this study. As a result of these systemic barriers, I followed a backup plan of using a convenience

sampling method to recruit participants through community supports, such as the provincial non-profit organization, the Myalgic Encephalomyelitis Association of Ontario (MEAO). I contacted the MEAO's Board of Directors who approved my study and then emailed the study information letter to their members (Appendix A). I also emailed and telephoned eight Greater Toronto Area (GTA) support groups and received responses from six support group leaders. These six leaders emailed my study information letter to their group members and four leaders invited me to their monthly group meeting to present information about the study.

In addition to developing connections with GTA group leaders, I was contacted by the leader of a Kitchener-Waterloo (KW) support group who conveyed interest in this study. I subsequently extended the geographical parameters of the study, assuming that geographical differences within the FM population would interconnect with other systems of embodied differences, such as gender, age, race, culture, and socio-economic status.

Screening potential participants.

Through the process of presentations, email, and word-of-mouth, I received indications of interest from 49 potential participants located across Southwestern Ontario. Although recruitment occurred between January and March 2013, most potential participants initiated contacted in January because they were excited that FM was garnering research interest. I screened these potential participants via structured telephone interviews to confirm they had: (a) been previously diagnosed with FM by a family physician and/or medical specialist, (b) availability for focus group participation, and (c) interest in engaging in an ABR project (see the screening script in Appendix B). I collected demographic information to ensure that the sample consisted of diverse individuals and obtained health history information (e.g. how many years

between the onset of symptoms and diagnosis, list of medications and co-morbid conditions, past and current FM treatments, etc.).

These telephone screenings were lengthy (e.g. ranging from 30 minutes to one and a half hours) because potential participants were socially isolated, eager to share details of their illness experiences, and had questions about the study's ABR component. Moreover, the process of explaining the informed consent form contributed to the length of the screening.

Many people with FM are vulnerable because they are marginalized within the healthcare system, socially isolated, unable to work, and living in poverty (Soderberg et al., 1999). Through the screening process, I observed other forms of vulnerability; namely, many potential participants self-reported cognitive deficits, a symptom of FM. In order to protect the rights of this vulnerable population, I both emailed and orally read the informed consent form to all potential participants in order to ensure that they understood the risks and implications of the study before providing consent (Appendix C). To promote trust and transparency, I asked potential participants to specify whether their data should either be included or excluded from the study in the event that they dropped out of the study. Furthermore, I explained that to protect confidentiality, I had developed study protocols, including: (a) using pseudonyms; (b) holding all interviews and group sessions in private rooms; (c) asking participants to not disclose each other's personal details outside of group sessions; (d) securing paper copies of participants' contact information in a locked filing cabinet; and (e) storing all electronic information in password-protected computer files.

Emergent design issues.

During the screenings, potential participants shared constructive feedback. After reflecting upon this feedback, I amended the method of data collection. For example, 13

potential participants were unable to attend multiple focus group sessions due to various reasons, including illness, geographical distance, time commitments, and discomfort with groups. However, these potential participants requested interviews because they wanted to contribute valuable information. Because of the participatory nature of this study, I accommodated these requests by adding ten in-depth interviews to the data collection process.

In addition to incorporating interviews into the study, I learned the importance of being flexible about the location of the focus groups. The focus group literature emphasizes the importance of holding focus groups in accessible locations to promote attendance (Asbury, 1995). I initially planned to promote attendance by holding the focus groups in an accessible building located near public transit (e.g. the downtown Toronto satellite office of Wilfrid Laurier University). After discussions with potential participants, however, I realized that lengthy travel would be an obstacle possibly resulting in attrition. As a solution, I divided potential participants into five focus groups based on geography: Mid-Toronto, Scarborough, Mississauga, York Region, and KW.

Preventing attrition.

Although I had enough participants for five geographically distinct focus groups, I was unsure if all five groups would be required during the data collection process. I had originally planned to facilitate three or four focus groups, a recommended number within the focus group literature (Asbury, 1995). However, I realized that the final number of focus groups would depend on the process of obtaining saturation through data collection and analysis. I decided to consecutively facilitate the focus groups in order to: (a) analyze the data (themes, observations and participant feedback) emerging within each group; and (b) use this analysis to revise the interview guide and body-map storytelling exercises before beginning a new group. I estimated

that this data collection process would take approximately six months, and therefore developed safeguards to prevent attrition of potential participants. For example, I periodically emailed updates about the study to all potential participants to confirm their continued interest in and connection to the study.

Creating and maintaining collaborative relationships.

During the recruitment and screening stage, I not only developed and maintained connections with potential participants, but I also built relationships with key stakeholders in the FM community. For example, I contacted and established ongoing dialogues with support group leaders, the respective presidents of both the national and provincial non-profit organizations for FM (the National ME/FM Action Network and the MEAO), and healthcare providers at Women's College Hospital and the Toronto Rehabilitation Institute. I also emailed my local Member of Parliament, Dr. Eric Hoskins, and initiated a meeting with my local Member of Provincial Parliament, Dr. Carolyn Bennett, in order to inform them about the study and invite them to future knowledge translation events. To prevent possible conflicts of interest, however, I did not engage in partisan politics by either requesting or receiving research funding.

Organization of data.

In order to organize the information about and dates of contact with stakeholders and potential participants, I created a master spreadsheet. From this master spreadsheet, I developed six more spreadsheets; one spreadsheet listed potential participants requesting individual interviews, while the other spreadsheets listed potential focus group participants based on geographical area. I then used these spreadsheets as contact guides when organizing each focus group. Furthermore, I placed participants' individual information in encrypted screening forms. I saved these documents on a password-protected computer, which only I could access.

Honoraria.

As suggested in the focus group literature (Kitzinger, 1995), during the telephone screenings, I offered potential participants financial incentives to promote recruitment. Potential focus group participants would receive bus tokens if they travelled by public transit to and from the group sessions, as well as a $100 honorarium divided into two installments of $50. One installment would be given during the first group session and the second installment would be given during the last group session. After adding individual interviews to the research design, I amended the study budget to additionally provide each interview participant with a $20 honorarium.

Data Collection

This study had three phases of data collection. In the first phase, I conducted all individual interviews and facilitated a pilot focus group. In the second phase, I facilitated two more focus groups. In the third phase, I returned to the field to collect additional data until saturation was reached.

Table 1: Focus Group Details

	Focus Group 1	**Focus Group 2**	**Focus Group 3**	**Focus Group 4**
Location	Midtown Toronto	Kitchener	York Region	Mississauga
Time	Mar-May 2013	Apr-June 2013	May-Jul 2013	Sept-Oct 2013
Female Participants	6	7	5	3
Male Participants	0	0	1	2
# of Sessions	5	6	6	5
# of Makeup Sessions	2	1	0	1
Session Frequency	Biweekly	Biweekly	Biweekly	Weekly
Duration	2 hrs/session	2 hrs/session	2 hrs/session	2 hrs/session

Table 1: This table breaks down each focus group by geographical location and gender, as well as by the number, frequency and duration of sessions.

Phase one: Individual interviews and pilot focus group.

Between February and May 2013, I conducted in-depth individual interviews with 10 participants (nine women and one man). Due to distance, one interview was conducted by telephone and one via Skype, while the remainder occurred face-to-face in participant-selected locations (e.g. six homes, one coffee shop, and one library) across the GTA, Waterloo, and Guelph. During these interviews, which ranged from one to two hours in length, I created an informal and flexible tone by inquisitively following the participant's lead to build rapport, while gently guiding and probing his/her narrative with the help of the interview guide (see the interview guide in Appendix D).

In addition to these individual interviews, the first phase of data collection included facilitating a pilot focus group. The rationale behind the pilot group was to: confirm the fit

between the research question and the methodology; gain experience with body-map storytelling; and, learn how many group sessions were required to give participants adequate time to discuss their healthcare experiences, create their body maps, and achieve closure. I planned to apply the lessons learned from the pilot group into the second phase of focus groups.

Between March and May 2013, I facilitated the pilot focus group in midtown Toronto. Out of the five possible geographies, I selected the midtown group based on the proximity to my home in order to reduce the risk of either commuting in or cancelling sessions due to late winter storms. In the focus group literature, there are varying opinions about the ideal size of a focus group; some authors recommend four to eight focus group participants (Kitzinger, 1995) while others recommend six to twelve participants (Asbury, 1995). Meeting in the middle of these suggestions, I selected a total of six focus group participants in order to create an emotionally safe and intimate environment. All six participants were female due to several requests for a women-only group environment. These participants met on a biweekly basis for five focus group sessions.

Before beginning the pilot focus group sessions, I invested an extensive amount of time, money, and emotional energy in preparatory activities. For example, I had to find an affordable, accessible, and private room located near public transit. After booking a free room in a public library, I visited this space and realized it was too small for facilitating art activities. I subsequently searched for a new location, but encountered obstacles around economics and accessibility; even with subsidy, community centres and large public library rooms were too costly, and many churches refused to rent rooms to non-members. With persistence and

advocacy, I eventually found an empathic administrator in a midtown Toronto church who was willing to rent space at a reduced cost.[11]

In addition to room rentals, other preparatory tasks included organizing the paperwork (e.g. informed consent forms, confidentiality agreements, emergency contact forms, attendance sheet, honoraria receipts, and body-mapping activity sheets) and acquiring art supplies. Gastaldo et al. suggest that researchers "provide a wide variety of crafting materials to ensure the participants are not limited" (2012. p. 21). Consequently, I visited art and dollar stores to purchase affordable, non-toxic, multi-media art and craft supplies. These supplies included yards of paper, tempera and watercolour paint, pencils, glue, tape, erasers, scissors, pencil sharpeners, rulers, paint brushes, sponges, markers, pencil crayons, felt, tissue paper, construction paper, feathers, and table clothes. I tested these supplies to ensure they were scent-free because many people with FM have chemical sensitivities. I also created my own body map to test the feasibility of the activities in terms of the time allocated and the concreteness of the instructions, revising the activities based on this firsthand experience.

[11] In comparison, when I later searched for space to hold two other focus groups, I found that churches with a social justice mandate were more willing to negotiate the cost of room rentals.

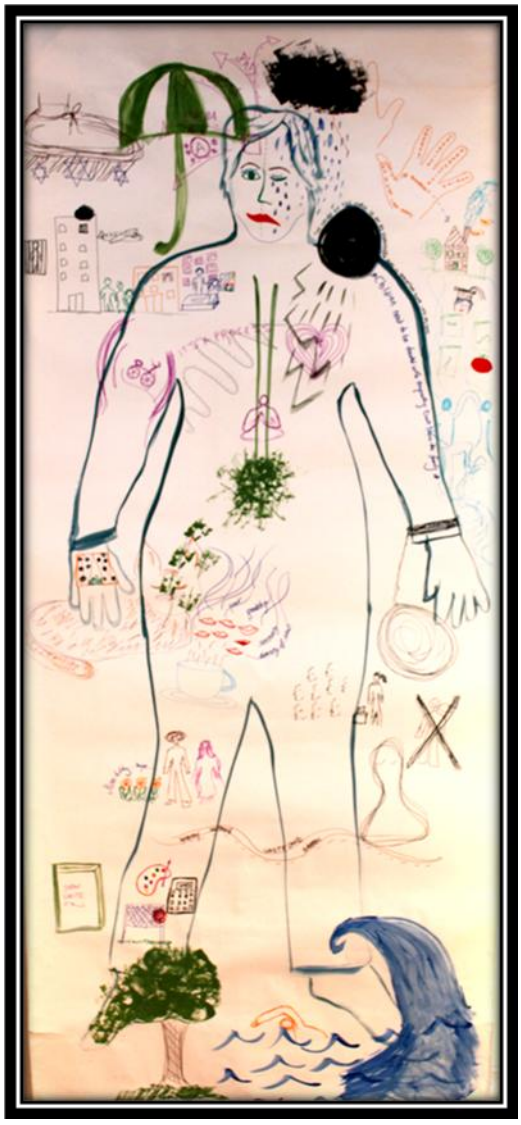


Figure 7: The body map I created as part of the pilot process.

Preparation for the pilot group not only involved administrative tasks, but also emotional readiness and anticipation. For example, I attended an art therapy workshop in order to learn how healthcare experiences can be visually expressed through art and how to be self-aware of the emotional triggers that occur during the art process. A final aspect of preparation involved consultation with a social work colleague who led therapy groups for trauma survivors. This colleague outlined the possible emotional triggers that research participants could experience, as

well as provided both prevention and intervention strategies to maximize the emotional safety of individual participants and the group as a whole.

Table 2: Focus Group Session Themes and Activities

	Session 1	**Session 2**	**Session 3**	**Session 4**	**Session 5**
Theme	Trust	Health & illness bios	Healthcare journey	Resilience & coping	Sharing
Activity	Rapport building	Art demo	Personal symbol	Message to others	Finishing touches
Activity	Safety rules	Body tracing	Diagnostic journey	Body scanning	Personal narratives
Activity	Semi-structured Qs	Self portrait	Care	Support structures	Group process review
Activity		Illness biography	Healthcare interactions	Drawing the future	
Activity	Group debrief & homework	Group debrief & homework	Group debrief & homework	Group debrief & homework	Group Debrief

As illustrated in table two, the pilot focus group involved five sessions. These sessions were audio recorded and ran for two hours, as recommended in the literature (Kitzinger, 1995).

The objectives of the first focus group session were to: develop group cohesion (e.g. emotional safety, trust, and rapport); clarify the focus of the study; and, and reduce anxiety by demystifying the process of body-map storytelling. Prior to the session, I arranged the chairs around a small table to promote an intimate environment and provided refreshments to maximize comfort. As participants arrived, I welcomed them and instructed them to review and complete the paperwork (e.g. signing the informed consent forms, confidentiality agreement, honoraria receipts, and emergency contacts forms). After the completion of these administrative tasks, I reviewed the study's purpose and shared both my personal and professional reasons for

conducting the study. I then asked participants to introduce themselves and their reasons for participating in the study.

Afterwards, the participants and I discussed the confidentiality of the focus group sessions (see Appendix E) and co-created a list of rules and responsibilities to help establish a safe environment (see Appendix F). One of the limitations of focus groups is that some participants may dominate the group while silencing others. In order to prevent this potential imbalance of power, I applied my social work knowledge of group dynamics and experience in group facilitation to discuss with participants the importance of being aware of others. I also worked with participants to anticipate how they would cope if they experienced emotional triggers. For example, I explained to participants that if they experienced emotional triggers they could speak to me and/or contact counselling services; I provided a list of counseling services on the last page of the informed consent form. In addition to brainstorming strategies to prevent emotional harm, the participants and I developed strategies for reducing the risk of physical harm. For example, if participants painted their body maps while seated on the floor, they could potentially strain their knees and backs (Hartman et al., 2011). As a solution, participants decided to take frequent breaks and specified if they wanted to create their maps on the floors, walls, or tables. This process enabled me to plan ahead in organizing the room for the next session (e.g. procuring individual tables, hanging paper on walls, etc.).

After the development of safety rules, participants took a snack break and then they shared their healthcare experiences of being diagnosed with FM (see Appendix D interview guide). During the final part of the session, I explained and answered questions about the methodology of body-map storytelling, and then participants took turns debriefing to achieve closure and prepare for the next session.

Several hours after the first focus group session (as well as all subsequent sessions), I modelled open communication and reinforced group cohesion by sending participants an email in order to: thank them for their participation and commitment to the study; remind them of the date, time, and purpose of the next group; and, attach documents, including the list of the safety rules generated in the session and the outline of the next session's body map exercises. I also sent an email reminder three days prior to the next group session.

During the second focus group session, I introduced body-map storytelling by sharing my own body map with the group, focusing on that week's theme: health and illness biography. In order to build trust and reduce participants' feelings of vulnerability, I briefly disclosed my own childhood journey through the healthcare system, incorporating both positive and negative experiences. I then showed the participants the wide variety of art supplies, provided a demonstration on how to mix paint colours, and encouraged them to use as either few or many art mediums as they desired (see Figures 8-11). In order to contain participants' anxieties about art, I answered their questions about the ways in which they could utilize the supplies.

Figure 8-9: Fran and Peanuts' respective body maps are examples of multi-media maps created with paint, markers, pictures, feathers, felt, and three-dimensional objects (e.g. Advil bottle located at the bottom left of Fran's map).

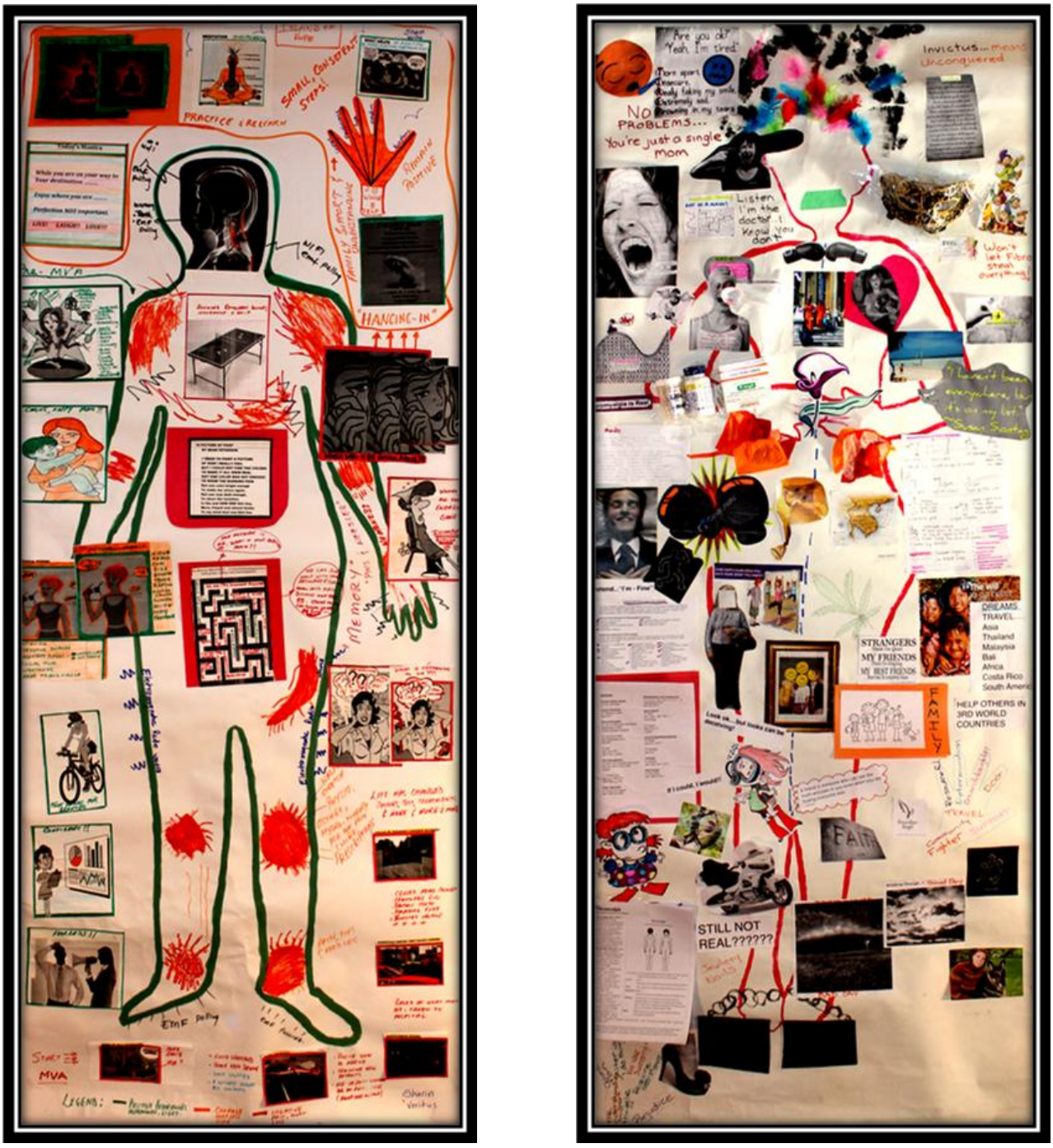


Figure 10-11: Sharin Veritus and Darlene's respective body maps are examples of maps primarily created with collage.

Participants partnered with each other to take turns tracing their figures on life size pieces of paper. While the majority of participants decided to be traced in a front profile, others selected side profiles (see Figure 12-13). Afterwards, participants chose to either hang their maps on the walls or spread them on five-foot-long tables, and then began creating their individual body maps (see Appendix G for body-map activity guide). I circulated around the room, spending time with each participant to ask reflective questions about their healthcare experiences, probe the meaning behind the colours and shapes they painted, as well as to provide feedback and encouragement. During these dialogues, I was careful to avoid imposing my own biases and beliefs, as there are multiple ways of knowing (Cornwall, 1992). At the end of the session, participants returned to the group to debrief about their body-mapping experiences in order to promote emotional containment. I digitally recorded all group discussions and participant-researcher dialogues, as participants' interpretations of their maps would later form the basis of the visual analysis (Gastaldo et al., 2012).

In comparison to the second session, the third and fourth focus group sessions had a similar format. Each session began with a brief discussion of the week's theme and corresponding art exercises; the focus of session three was the healthcare journey and session four was resilience and coping. I illustrated these exercises and made them less abstract and more concrete by narrating parts of my own body map. Participants then continued their own work while taking breaks to talk to other participants to generate ideas (see Appendix G for list of body-map exercises). I circulated around the room, spending equal amounts of time with each participant. Each session ended with a debriefing dialogue.

During the fifth session, each participant spent approximately 15 minutes presenting her body map. After these presentations, I facilitated a discussion about whether the process of body-

map storytelling prompted ideas or strategies about how healthcare providers could better meet their physical and emotional needs. Finally, I asked participants to share their experiences about the focus group process and provide feedback for the purpose of strengthening and revising the body-map storytelling methodology.

To reduce the risk of attrition and to promote participants' confidence and productivity, I facilitated two makeup sessions at participants' homes. During the first makeup session, I helped two participants, who had missed the second focus group session, begin their body maps. During the second makeup session, I helped another participant, who had missed three focus group sessions due to FM-related illness, finish her body map.

The collaborative process of body-map storytelling.

During the pilot focus group, I realized that body-map storytelling is a collaborative process among researchers and participants, and thus the co-creation of ideas and artwork is an inevitable part of the endeavour. For example, I helped participants brainstorm ideas by probing their thoughts about what images they wanted to create and guiding them towards an action plan. At the same time, I tried to reduce researcher bias by adopting a stance of reflexive inquiry; I validated participants' visions while consistently reflecting upon my responses and reactions in order to prevent imposing my own views.

Participants' body maps were not only shaped by their interactions within the group sessions, but also by their continued work outside of these sessions. For instance, I provided brief homework exercises for participants to reflect upon at home, enabling them to come to the following focus group session prepared with ideas for the remaining activities. Some participants became highly engaged and chose to take their body maps home to work on in between focus group sessions. Participants' engagement in the mapping was also evident by their abilities to

look beyond the art supplies provided in the group; some participants brought their favourite art supplies from home (e.g. tissue paper), while others asked me to provide further materials (e.g. cotton balls and string to represent their symptoms of fibro fog). Another trend was participants researched and selected images from both on-line and print media sources to incorporate into their maps; they brought duplicate images to share with fellow participants who, in turn, became inspired to also use these images. By sharing resources, participants unintentionally influenced each other and created body maps with overlapping themes. However, I felt it was important to respect participants' collaboration because it fostered community, as well as a spirit of self-efficacy and collective empowerment. During data analysis, I addressed the ways in which the findings of the study were potentially impacted by: (a) the collaboration among researcher and participants and (b) the movement of body maps between focus group and home environments.

Phase two: Focus groups.

After receiving the feedback from the first focus group, I revised the body-mapping exercises and then concurrently facilitated a focus group with seven female participants in Kitchener (located in the WLU Faculty of Social Work auditorium) and a mixed gender focus group with one male and five female participants in York Region (located in a church room). Each of these two focus groups had a similar format to the sessions in the phase one focus group except minor variations were made to the exercise guide. Furthermore, I added an extra session due to participants' feedback that more time was required to complete the exercises.

Phase three: Returning to the field to collect further data.

After the completion of phase two, I sent a report of my preliminary research findings to my dissertation committee. Although the study focused on gender, only two men had participated thus far. Given this fact, the committee and I decided that I would begin a third

phase of data collection with the objective of exploring gender differences in healthcare experiences. To achieve this objective, I facilitated a fourth mixed gender focus group with two male and three female participants in a church located in Mississauga. Although the format was similar to the previous three focus groups, I facilitated the sessions on a weekly instead of a biweekly basis to expedite the data collection process. Compared to the previous focus groups, this group had fewer participants, and therefore I reduced the number of group sessions from six to five; by having fewer participants, I was able to spend more time providing support to each person during the body map activities. Furthermore, based on participant feedback, I began each focus group session with a five-minute meditation in order to help participants' feel more grounded, relaxed and connected before engaging in the body-mapping activities. The participants and I both observed and discussed that there was a calming change in the room's energy after the meditation.

In addition to adding a fourth focus group, I revised the methodology in order to facilitate body-map storytelling on an individual basis with a male participant who could not attend the focus group sessions. The participant and I met at his home for four sessions. The first session involved an in-depth interview about the participant's healthcare experiences. The second and third sessions focused on creating the participant's body map. The fourth session was the participant's presentation of his map. In between sessions, the participant and I had weekly telephone conversations to help reduce his anxiety about the artistic process and promote the generation and exploration of his ideas.

Figures 12-13: Snay and Penny's respective body maps are examples of unique body profiles.

Data Analysis

As recommended in the literature about grounded theory, I concurrently collected and analyzed the focus group data (Webb & Kevern, 2001). After each individual interview and focus group session, I wrote field notes in order to reflect upon the individual/group dynamics, as well as the illuminating themes that arose during the interviews/sessions (see Appendix H). These notes captured both the verbal and non-verbal richness of the data, including participants' use of humor and the expression and intensity of their emotions (Carey & Smith, 1994). I hired students to transcribe the digital recordings of the interviews and group sessions and received a total of 40 transcripts, including: twenty-two focus group sessions; four individual body-mapping makeup sessions for focus group participants; four individual body mapping sessions with a male participant; and, ten individual interviews. I cleaned all 40 transcripts (e.g. revision of grammatical errors and deletion of confidential information); each transcript was between 50 to 80 pages in length. For this dissertation, I focused on coding and analyzing the focus group sessions because of the volume and richness of the data. During the spring of 2015, I plan to code the individual interviews, compare these interviews to the focus group data, and report these findings in journal manuscripts.

Textual analysis.

After cleaning the focus group transcripts, I loaded them into the software program NVivo 10. I then coded and analyzed these transcripts using constructivist grounded theory (see Appendix I). This inductive approach involved reading the transcripts multiple times, coding line-by-line, and creating initial codes grounded in the data. At the same time, this process was deductive; the study's theoretical framework guided my focus on developing codes, which arose from feminist poststructural concepts, such as how issues of power, difference, and meanings

were constructed through context and language. I was also guided by the concept of intersectionality, exploring the ways in which interlocking forms of oppression were experienced in participants' lives. I maintained a stance of "theoretical sensitivity" to explore the nuances of meaning within the data (Johnson, Repta & Kalyan, 2012, p. 55). In sum, I balanced the need to be both inductive and deductive by creating codes that stemmed from theoretical concepts while remaining open to new codes that emerged outside of a preconceived framework.

After the development of initial codes, I refined these codes and developed axial codes; axial coding involved organizing the data into categories and subcategories (see Appendix I). This organization of data led to the identification of theoretical codes, which are higher-order relationships among the more concrete codes Charmaz, 2006). The goal of this coding was to obtain "thick description" about participants' experiences (Charmaz, 2006), as well as to constantly compare the data.

> [C]omparing data with data means: (1) comparing different people's situations, beliefs, behavior or accounts of the same type of event or issue, (2) comparing data from the same people at different times and (3) comparing properties found in the data with other properties (p. 1168).

Charmaz's use of constant comparison is compatible with Carey and Smith's (1994) view that focus group data should undergo three levels of analysis: the individual, the group (interactional and sequential analysis), and the comparison of individuals within the group. These three levels of analysis fit with constructivist grounded theory, as categories for individual and group processes can be created and then compared. As such, I compared individual participants both within and across groups. For example, I analyzed differences among male and female

participants, such as how their interactions with healthcare providers varied based on gender and other forms of difference.

In the final stage of analysis, I developed a theory grounded in the data. I spent several months conceptualizing and re-conceptualizing this theory in order to accurately capture the nuanced complexity of the data, moving beyond descriptive themes to a theory about social processes and interactions.

Visual analysis.

In addition to the transcripts, I analyzed participants' body maps. Unfortunately, there is a dearth of literature in both the health sciences and social sciences about methods of visual analysis. However, Gastaldo et al. (2012) explained that body maps:

> [S]hould be analysed in their integrity, which includes the process of creating it (verbatim and field notes), the body map itself, and the narratives that accompany it (*testimonio* and *key*). The purpose of the analysis is not to psychologically evaluate the participants through their art, but to gain insight into certain aspects of their logic, aspirations, desires, material circumstances, and ways of handling particular issues (p. 18).

Given the importance of balancing participants' maps, verbal narratives, and creative processes, I developed a multilayered visual coding scheme. This coding scheme was influenced by constructivist grounded theory and involved eight stages. First, I followed an inductive approach by reviewing all of the body maps (as one would repeatedly read transcripts) to familiarize myself with the data. This approach involved rolling out the life-size body maps on a long table in order to examine all parts of the maps.

Second, I organized the visual data by photographing the body maps and uploading these photographs into NVivo 10. I analyzed the life-size body maps rather than the photographs of the

maps because many of the hand-drawn details could not be seen in the photographs. However, the rationale behind uploading the photographs was to create a system of organization. I used NVivo to consistently organize the codes and memos, which emerged from the visual analysis, and to ensure that both the visual and verbal data was contained within the same software program. This process enabled me to later compare and merge codes from both the visual and verbal data.

Third, I created initial codes based on similarities and differences in the: use of color; themes and discourses; types of representations (e.g. words, picture collages, and hand-drawn images); size, repetition, and location (e.g. symbols situated inside and outside of the body) of the images and words.

Fourth, I compared the participants' body maps to their audio-recorded verbal presentations of their maps, which occurred during the final session of each focus group. Because this study was participatory, it was important to honor and not misinterpret the meanings participants' ascribed to their maps. Furthermore, this process of matching participants' images to their narratives was a method of ensuring that the initial codes were grounded in the data. Through this process, I also refined the codes by renaming and redefining them to improve the clarity of meaning.

Fifth, I grouped the codes into three themes: conceptual content, tone, and elements of design. Conceptual content refers to the healthcare-related themes represented by words and images in the body maps. Tone refers to the mood evoked through the images and words that participants' used to represent their positive and negative healthcare experiences. Elements of design refer to the visual aesthetics of the body maps; this is a conceptual framework borrowed from fine art theory. For centuries, the elements of design, which are considered universal, have

helped guide the ways in which artists have created their artwork and art critics have interpreted these works. The elements of design include: line (horizontal, vertical, diagonal lines); color; value (the hue and tone of the color); shape (the two-dimensional outline of objects); form (the three-dimensional creation of objections and area through shading); space (the positive space of the object and negative space surrounding the object); and, texture. Within a piece of art, repeated elements (e.g. color and line) and proportion (e.g. evenly balanced shapes) evoke a sense of visual harmony, unity, movement, and rhythm, while a variety of elements creates visual interest (C. Skop, personal communication, January 2014). I used several of these elements of design -- specifically color, texture, shape, and space -- to guide my analysis. I also looked at the ways in which these elements created visual harmony, rhythm, movement, and interest.

The sixth stage of the visual analysis involved an exploration of the ways in which the themes of conceptual content, tone, and elements of design were co-constructed both within and across groups. For example, the image of healthcare as a journey was repeatedly constructed by participants belonging to both the same and different focus groups. These within-group commonalities highlighted that participants shared ideas with each other as they created their maps. In comparison, the across-group commonalities signified both the universality of certain images and metaphors. These commonalities also shed light as to the ways in which I was inspired by the participants, thereby unintentionally co-constructing meaning across groups. For example, at times, when I described body-mapping exercises to participants, I illustrated these exercises with themes that arose in other focus groups. These themes may have resonated with certain participants and influenced their artistic process.

The seventh stage of visual analysis focused on intersectionality. Within each of the three themes, I selected a variety of salient codes and then examined systems of embodied differences in these particular codes. For example, in the code "negative healthcare experiences," which was categorized under the theme of conceptual content, I compared the images created by male and female participants. I also compared these images to the transcripts to capture both the verbal and non-verbal meanings. This process was deductive because I specifically examined participants' perceptions of how their different social locations influenced their interactions with healthcare providers.

The eighth stage involved narrowing the focus of the visual analysis for the purpose of the dissertation study. In particular, I focused on the codes that: (a) were within the theme of conceptual content; (b) described healthcare experiences; and (c) richly illustrated salient concepts emerging from the transcript analysis. I wrote multiple drafts of the findings, including a chapter that solely focused on the visual analysis by presenting case studies of three participants' body maps. However, I eventually realized that the most suitable format for clearly and succinctly answering the study's research question was to integrate both the verbal and visual findings. As such, in this dissertation, I solely report the body-map themes that correspond to the themes within the transcripts. After the completion of the dissertation, however, I will prepare manuscripts, which report the visual findings from the body maps, and submit them for publication in peer-reviewed journals. I will also return to the data for further analysis of codes that were significant yet unrelated to the central focus on healthcare. For example, I found rich information about participants' identity and their use of the elements of design.

Figure 14: Photographing the body maps for the purpose of data analysis.

Knowledge Translation

I obtained participants' informed consent in order to organize a community art gallery to showcase the body maps. The objective of this gallery will be to share participants' visual narratives about their experiences in the healthcare system, thereby raising awareness and decreasing stigma (Baerg, 2003). In order to maximize public exposure, I plan to host this event to coincide with the National ME/FM/MCS Awareness Day on May 12, 2015. Invitations will be sent to participants' families and friends, academics, community members, policymakers, and healthcare providers. In order to respect the participatory nature of this study and the participants' right to ownership, the body maps will be returned to participants after the gallery

show. However, I obtained informed consent to photograph the body maps for use in future knowledge translation exercises. For example, I will present the visual research findings at healthcare conferences and clinical workshops because I am committed to interdisciplinary collaboration and to improving healthcare outcomes. I will also design a website, which showcases the body maps, as an ongoing educational tool for the FM community.

Lessons Learned from Utilizing this Methodology

Body-map storytelling is a relatively new research methodology. As such, it is important to transparently share not only the procedures for data collection and analysis, but also the struggles and issues that arose during this methodological process. I view these struggles as invaluable opportunities for learning and growth. I hope that the lessons I have learned can help prepare other researchers who plan to utilize this methodology.

For a doctoral dissertation, this study had a large sample size and produced an extensive amount of data. I included a large number of participants, as I anticipated that some participants might drop out of the study; the research design involved an ongoing commitment from participants living with chronic illnesses. I was delighted that all participants remained in the study. During the process of data analysis, however, I was overwhelmed by the volume of transcripts. As a solution, I coded the focus group data, leaving the interview data for future coding and analysis. Upon reflection, an alternative strategy for future studies would be to collect data from either focus groups or interviews, and then amend and expand the data collection method if there was a shortage of potential participants.

The process of collecting data not only yielded an extensive amount of information, but was also intensive and rigorous. Consequently, after I completed data collection, I experienced symptoms of burnout such as reduced work productivity and a weakened immune system. I later

realized that this burnout was a form of vicarious trauma. My trauma response was triggered through the process of facilitating interviews and focus group sessions with participants who shared personal narratives of trauma, including childhood abuse. Some participants were also traumatized from living with a contested condition that their support systems and healthcare providers did not believe was real. Given my experiences, I suggest that researchers planning to utilize body-map storytelling should first anticipate the risk of vicarious trauma and develop strategies to minimize this risk.

Despite the potential for vicarious trauma, body-map storytelling can foster a process of healing, personal growth, and community. For example, many participants described that the process of body-map storytelling was therapeutic and reduced their social isolation. Some participants exchanged email addresses, and one group of participants planned to continue meeting on an informal basis after the completion of the research. I will elaborate on this finding in future journal manuscripts. At present, however, I would like to emphasize the importance of this methodology's potential therapeutic value. I suggest that researchers should either have or obtain training in group facilitation in order to ensure that participants' feel emotionally contained and consistently supported throughout the research process.

A final issue that arose regarded participants' selection of pseudonyms. In the spirit of participatory action research, I asked the participants to select their own pseudonyms for use in the study. Some participants selected regular-sounding names whereas others selected nickname-like pseudonyms, which reflected personal meanings and/or humour. However, my dissertation advisors expressed concern that nickname-like pseudonyms might cause some readers to take the findings less seriously than they should. They suggested that pseudonyms that seemed more like usual names might be advisable. Consequently, I asked participants if they would be willing to

consider selecting different pseudonyms that were more similar to regular names than nicknames. However, I informed participants that I would respect their decision to keep their original pseudonyms. Most participants with nickname-like pseudonyms were open to considering different names but decided to keep their original pseudonyms. In comparison, several participants expressed concern that the name change request perpetuated the delegitimizing discourse that people with FM should appear a certain way to be accepted by the medical community. I apologized to these participants, explaining that the name change request was based on the need to be strategic in relaying information to the public about controversial topics. I also reinforced that the purpose of the study was to shed light on the legitimacy of FM and not to perpetuate invisibility. This experience increased my awareness that pseudonyms can be a personal expression of identity and should be maintained despite potentially negative public perceptions.

CHAPTER FIVE - FINDINGS

EXPERIENCES OF COMPROMISED HEALTHCARE

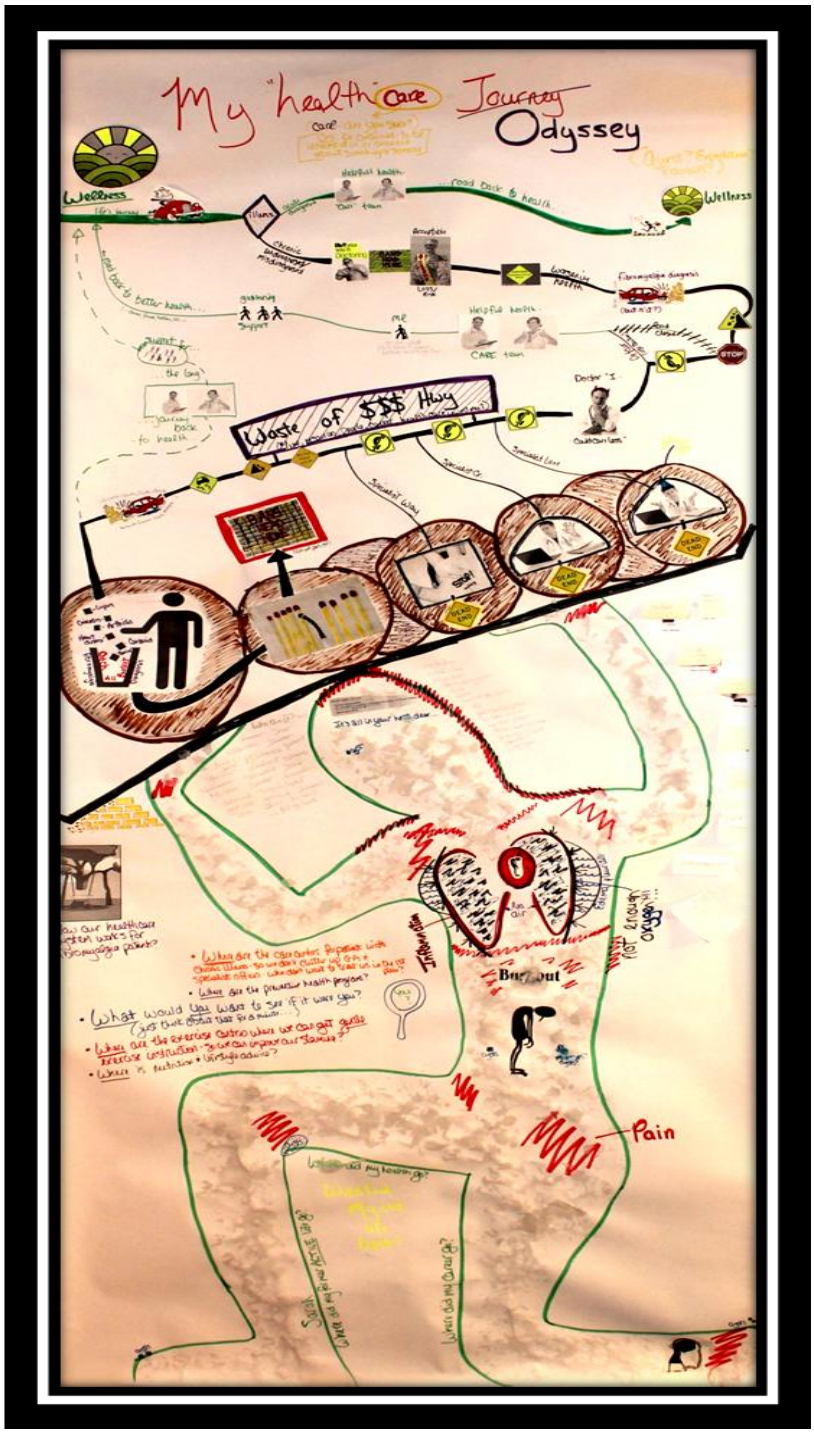


Figure 15: This chapter opens with Sarah's body map because she illustrates how patients with FM are forced to carry the weight of the healthcare system.

Both the individual interviews and focus group sessions produced a very large amount of rich data. However, in the remaining chapters of this dissertation study, I solely report and discuss the findings that emerged in the focus group sessions. I have narrowed the focus in order to examine the nuanced complexity of participants' verbal and visual representations of their healthcare experiences[1]. In this chapter, I will first describe the demographics of the focus group participants and then report the primary finding about participants' experiences of compromised healthcare. I review how the majority of participants experienced compromised healthcare due to structural barriers, such as policies that impeded the delivery of services to FM patients, and interpersonal barriers, such as providers' uncaring interactions towards patients. Finally, I will describe the ways in which participants' systemic experiences of compromised care were emotionally traumatic, compounding the existing stress of living with a contested condition. Throughout this chapter, I illustrate the themes and subthemes about compromised care through participants' interwoven narratives and body maps.

Participant Demographics

This study had a total sample of 35 participants diagnosed with FM. Out of this sample, 10 participants completed in-depth individual interviews, 24 participants created body maps within a series of focus group sessions, and one participant created a body map during a series of individual interviews[2]. The following section reports the demographic data of the 25 participants who completed body maps.

[1] In future writings, I will compare and report the findings from both the interview and focus group data.

[2] Although this participant was unable to attend focus group sessions, he was included in the study because further data about gender was required.

Identified Gender, Age, Marital Status, and Children

During the recruitment stage, I had telephone conversations with potential participants and obtained demographic information. As part of the demographic questions, I asked participants to identify their gender in order to prevent making assumptions about their self-conceptualizations. Most participants identified themselves as women between the ages of 40 and 69 (Table 3) who were married with children (Table 4).

Table 3: Participants' Age and Identified Gender

Age Group	Women	Men
30-39 Years	1	1
40-49 Years	6	1
50-59 Years	9	2
60-69 Years	5	0
Totals	**21**	**4**

Table 4: Participants' Marital Status and Children

Marital Status	Participants	0 Children	One or More Children
Single	2	2	0
Common Law	1	1	0
Married	16	2	14
Separated	2	0	2
Divorced	4	0	4
Totals	**25**	**4**	**21**

Race, Culture and Religion

Regarding race, 18 participants identified as White, four identified as South East Asian, two identified as Black and one identified as Chinese. All participants who identified as White reported that their birthplace was Canada. Many of these participants defined their culture as Canadian while others described themselves as belonging to and/or descending from varied cultural backgrounds (e.g. British, Italian, second generation Polish). In comparison, most participants who identified their race as Black, South East Asian, and Chinese reported being born outside of Canada. They described their cultures based on either their own or their parents' originating countries ("Jamaican") and regions ("East Indian"), as well as by visible identities ("identify as Canadian, look South Asian").

The majority of participants identified a diverse array of religious affiliations, including Catholicism, Christianity, Protestantism, and Judaism. In comparison, six participants reported not having religious affiliations, one participant identified as a non-practicing Catholic, and one participant identified as an Atheist. Furthermore, several participants defined themselves in terms of their spiritual beliefs (e.g. "multi-faith," "oneness in all" and "oneness for humanity").

Education and Employment

Most participants were highly educated. Twenty participants had completed post-secondary diplomas and degrees, two participants had some post-secondary experience, and three participants had received high school diplomas. At the time of data collection, only one participant worked full-time and two participants worked on a part-time basis. Twenty-two participants were unemployed and cited their inability to work as a consequence of FM. These participants, however, had worked prior to the onset of FM and at various stages of illness. Most unemployed participants reported that they struggled financially and received income from the Ontario Disability Support Program or the Canadian Pension Plan Disability Program. In terms of professional backgrounds, participants either previously or currently worked in fields such as business (e.g. self-employed, family-run, and large companies), education, finance, healthcare, homemaking, information technology, law, marketing, and merchandizing.

Illness History

Participants reported experiencing the onset of FM in varied ways. For example, four participants explained that their FM began in childhood and adolescence. Five participants described that the onset of FM occurred in adulthood in the form of gradually increasing pain (e.g. back and neck pain); three participants reported that their FM symptoms began during prolonged illnesses, such as the flu and pneumonia, which they never fully recovered from. In

comparison, eight participants described that the onset of FM suddenly occurred as a result of physical traumas, including motor vehicle accidents, sports and workplace injuries. Others reported traumas included a stroke, ruptured appendix, and difficult childbirth. In addition, one participant reported that her FM "happened over night" after an emotionally traumatic workplace event.

All participants were diagnosed with FM between 1985 and 2011 and had lived with FM for a mean of 11 years and a median of nine years. Many participants visited multiple doctors over the course of many years before receiving a diagnosis of FM while others were diagnosed in a more expedient manner. Twenty-one participants were diagnosed with FM by rheumatologists, while other participants were diagnosed by medical specialists (e.g. neurologists, physiatrists, and sports medicine doctors). In order to alleviate and/or manage their FM, most participants had tried numerous treatments within the fields of allopathic medicine and complementary and alternative medicine (CAM).

Comorbid conditions.

Twenty-three participants experienced comorbid conditions. Because participants self-reported these conditions, I cannot verify whether they were formal medical diagnoses. Another complexity involved timeline; participants reported suffering from multiple comorbidities, and some of these conditions preceded the onset of FM while others occurred in conjunction with or after the time of onset. Moreover, it is unclear whether the comorbidities were either part of the constellation of FM symptoms or separate diagnostic categories. For example, one participant stated that she did not have comorbid conditions because all of her symptoms fell under the FM umbrella. A final limitation is that I did not include demographic questions about family histories

of illnesses and diseases. However, one participant reported that her son had multiple chemical sensitivities while another participant reported that her mother had a diagnosis of FM.

Many participants reported experiencing comorbid conditions that are consistently associated with FM in both the qualitative and quantitative literature. For example, eight participants suffered from chronic fatigue syndrome, one had multiple chemical sensitivities, one had lupus, three experienced migraines, five had irritable bowel syndrome, and two had bladder problems (e.g. "bladder issues" and "urinary tract infections"). Four participants reported digestive problems (e.g. "acid reflux," "gastritis," "digestion-related issues," and "stomach issues"). Several participants had hernias and two had ulcers. Four participants had sleep apnea while one described experiencing "un-restorative sleep." Two participants had diabetes and one reported "endocrine problems." Three participants reported hypertension and one had pericarditis. Several participants reported cognitive impairments, including "memory loss" and "concentration issues." One participant had asthma, several reported allergies, two had "sinus pain", and one had a "chronic sore throat." Many participants also reported having B12 deficiencies. Regarding musculoskeletal conditions, five participants had arthritis, three had osteoarthritis, one had rheumatoid arthritis, two had herniated discs, and one had degenerative disc disease. Others reported "lower back injuries," "brittle bones" and osteopenia. One participant described experiencing "continued pain" from shingles, one had "head pain" and several had pinched nerves.

It is important to note that four participants were cancer survivors; three had thyroid tumours removed while one had a double mastectomy due to breast cancer. Several participants also reported living with benign tumors. Furthermore, one participant reported a family history of breast cancer.

In addition to physical illnesses and diseases, some participants reported histories of mental illness. For example, six participants had depression, three had Post Traumatic Stress Disorder, two had anxiety, one had obsessive compulsive disorder, and one had bipolar affective disorder. Two participants also suffered from acquired brain injuries. Some participants explained that their mental health issues predated their FM while others experienced mental health concerns as both secondary to and as a result of the FM.

Demographic Summary

In summary, this sample was homogeneous in some respects (e.g. gender, age, marital status, race, education level, existence of co-morbid conditions) and heterogeneous in other ways (e.g. culture, religion, and professional backgrounds). The homogeneity can be partly attributed to the study's method of recruiting participants via fibromyalgia support groups. Support groups can potentially attract people who have familiarity with and the ability to access community resources. Conversely, people who are recent immigrants and speak English as an additional language may be less familiar with these community resources. Furthermore, the homogeneity of the sample echoes the findings of Canadian and American general population surveys, which estimate that FM afflicts more women than men and that the majority of these women are over the age of 50 (White et al., 1999c; Wolfe et al., 1995). At the same time, the heterogeneity of the sample is reflective of the diversity of the population within the Greater Toronto Area and Kitchener-Waterloo.

Participants' Experiences of Compromised Cared within the Healthcare System

The primary finding of this study was that the majority of participants experienced compromised healthcare within the allopathic medical model. This finding was evident both within and across the four focus groups despite the fact that participants inhabited different social

locations[3]. Based on participants' narratives, I have defined compromised care as the ways in which the provision of ethical, equitable, and adequate healthcare was impeded by barriers at both the macro- and micro-level. On the macro-level, governments and institutions regulate care through the development, implementation, and reinforcement of policies that define how, why, when, where and to whom services are delivered. On the micro-level, these policies govern healthcare providers' clinical conduct and interactions with patients. Within these interactions, care is the process by which providers treat patients in both a clinical and relational sense.

The interconnection of micro- and macro-level barriers in the provision of healthcare is illustrated in Sarah's body map[4]. When describing the title of her body map, for instance, Sarah deconstructed the concept of "healthcare."

> [T]he subject was my healthcare journey. So I put "my 'health' care journey" and then I realized it's not a journey, *it is a struggle*. It's an odyssey so – and I looked at healthcare. So I deconstructed [the term healthcare] – so first of all I put health in quotes because, you know, nobody seems to be caring – to care if you have health. Then I looked at care, so this is one that you have to go pay attention to, so I put "care, are you sure"? Um, and then I put the dictionary definition of care, "to be concerned, to be interested in or care about something or someone."

Sarah highlighted how the "struggle" and "odyssey" to find and receive good or helpful healthcare is an individual experience situated within a larger system. Sarah's questioning of

[3]Although the majority of participants described experiences of compromised care, some participants reported either solely positive or a mixture of both positive and negative healthcare experiences. In chapter eight, I report the findings about participants' positive healthcare experiences as an entry point for examining possible solutions to improve the quality of healthcare for the FM population.

[4]In this study, participants selected their own pseudonyms in order to ensure their identities remained confidential.

whether the healthcare system truly "cared" was echoed by many participants in discussion of structural and interpersonal barriers.

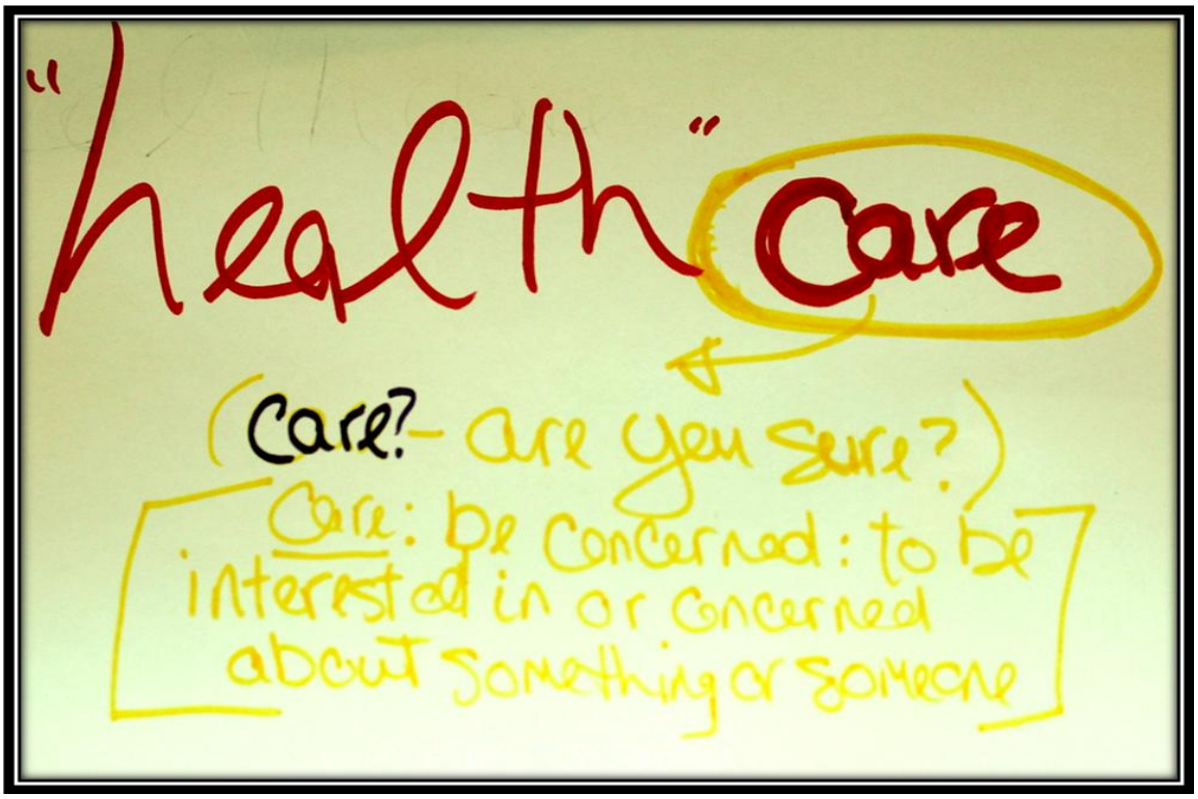


Figure 16: In the title of her body map, Sarah problematized the concept of healthcare.

Compromised Care: Participant Descriptions of Structural Barriers

Some male and female participants possessed a critical awareness that patients with FM did not receive proper care due to structural barriers. These participants discussed that structural barriers to care included the regulations of OHIP billing practices, the absence of a clear path for navigating FM healthcare services, and the lack of continuity of care for patients with FM.

OHIP regulated billing practices.

A participant Scarbro felt that providers prioritized the monetary task of attaching patients to billing codes over the clinical act of addressing patients' healthcare needs.

> It's very disempowering to be in the system… I just feel *I'm* just there to keep all these healthcare people employed. If I get care or not is irrelevant as long as they can figure out a billing code that is associated with me… It's a systemic issue.

Scarbro argued that patients with FM suffered from chronic, complex, and comorbid conditions, and therefore required longer OHIP covered medical appointments than are currently available.

> It's a half a day appointment, maybe took my whole week to get over there [to the medical appointment]. And when you [the doctor] only give me five, ten minutes [to describe the health issue]… And I just started telling you [the doctor] my story and I forgot half of it, it doesn't work for a fibromyalgia patient. It totally fails you. So even in six appointments, you can't really get a story straight… maybe the combined number of doctors in Ontario don't know, because they don't have the time… Maybe there's an initial appointment for 15 minutes… It doesn't work. It fails the fibromyalgia patient, how the current medical billing system works...

Figure 17: Scarbro argued that like Oliver Twist, the FM population requires "more" healthcare.

In addition to billing regulations, some participants raised concerns that fiscal pressures prompted medical doctors to "kick" patients with FM out of their practices, and thereby placed patients at risk for having either undiagnosed or misdiagnosed comorbid conditions.

> …I get the impression that a lot of us have a lot more than just fibromyalgia going on but they [doctors] just couldn't care to diagnose it. So you get "bluff your way out doctoring." I have "bang head here" [written on body map]… I feel like I'm suffering

through the consequence through managed healthcare in Canada. That really they [doctors] don't want to see us… but they waste a lot of money trying to kick us out of the system whereas you could be providing services so that we can help ourselves that don't cost that much. - *Sara*

Sarah used the term "bluff your way out doctoring" to describe how doctors were financially motivated to make excuses and deny patients' services such as appropriate diagnoses. Sarah felt that this system of "managed healthcare" resulted in patient suffering and head-banging frustration.

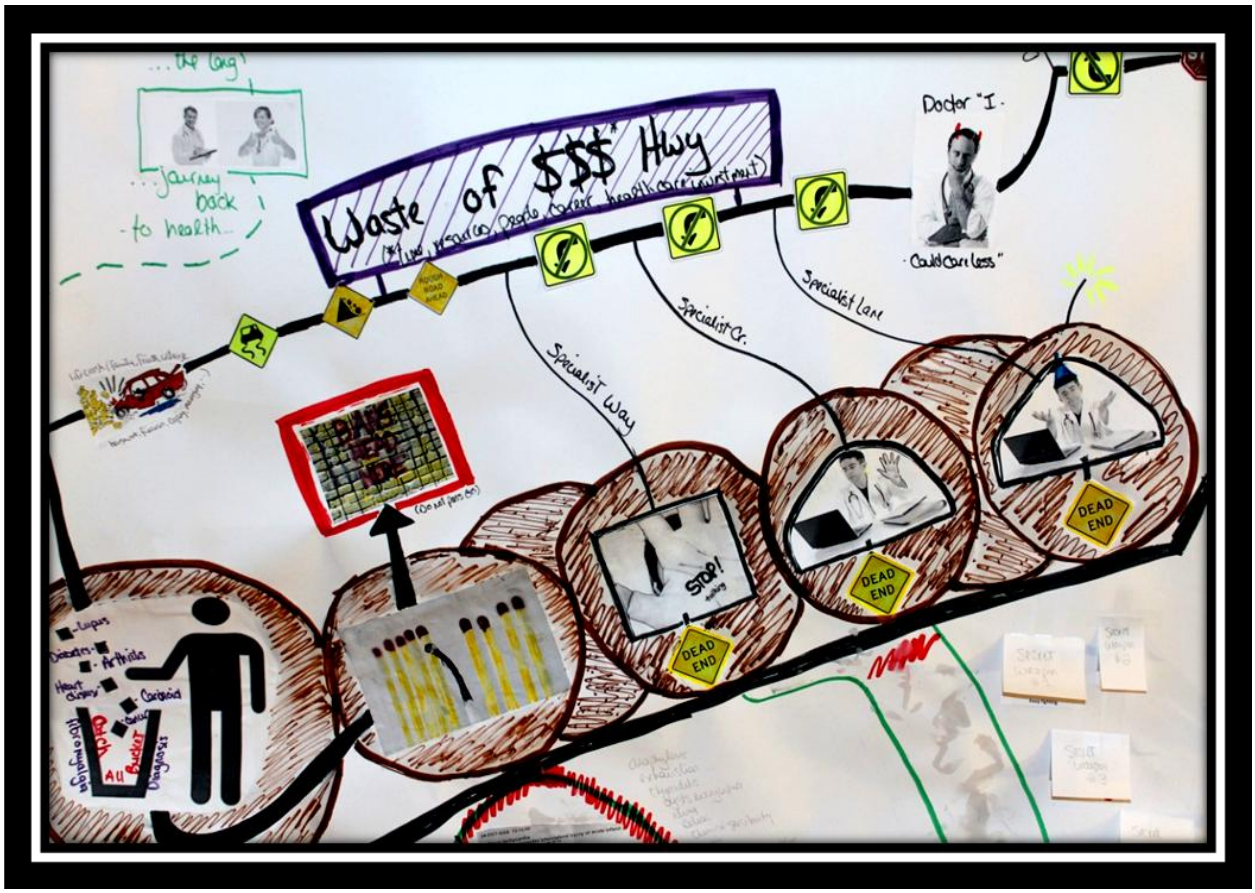


Figure 18: Sarah's "Waste of $$$ Hwy" depicts that patients with FM travel down the rocky road of a fiscally and clinically inefficient healthcare system and shoulder the burdens of this system.

Lack of a "clear path" for health system navigation.

Echoing Sarah's concerns, many participants discussed that Ontario's healthcare system was both economically and clinically inefficient due to a lack of integrated services. These participants experienced the healthcare system as multiple silos of services divided into specialties. This system, which has the potential to negatively impact all patient populations, was difficult for FM patients to navigate partly due to a lack of standards requiring communication and partnership between specialty services.

> If we had diabetes, we wouldn't be having this conversation because there is a clear path, there are programs, there is medication and it is clear-cut. But with fibromyalgia, like my experience was I was going to physiotherapy… and it was actually the physiotherapist who said I'm going to send you to a… naturopath doctor but he's a medical doctor. And he's the one who sent me to a rheumatologist and it was she that diagnosed me. That took almost three years even to just get an appointment with her to go and see her. So it is not just the fact… you might have these symptoms let's go and see a specialist; it's the waiting time… And then she gave me a diagnosis, and then sent me down to [hospital name] and it took me again, another two and a half years to get an appointment there. And the rheumatologist that I had seen said, when I tried to do a follow-up with her, she said she isn't taking any more fibro patients. - *Anna*

In her narrative, Anna discussed that the healthcare system had "clear-cut" service pathways and treatment protocols for diabetes and other diseases with known causes. In contrast, the system lacked a "clear path" for the diagnosis and treatment of FM, and therefore patients were forced to travel through a maze of fragmented services

The image of a path (or lack thereof) was a prevalent theme in many participants' body maps. In order to symbolize their healthcare journeys, for example, five participants drew mazes, four participants drew roads, four participants drew circular images, and two participants drew roller coasters.

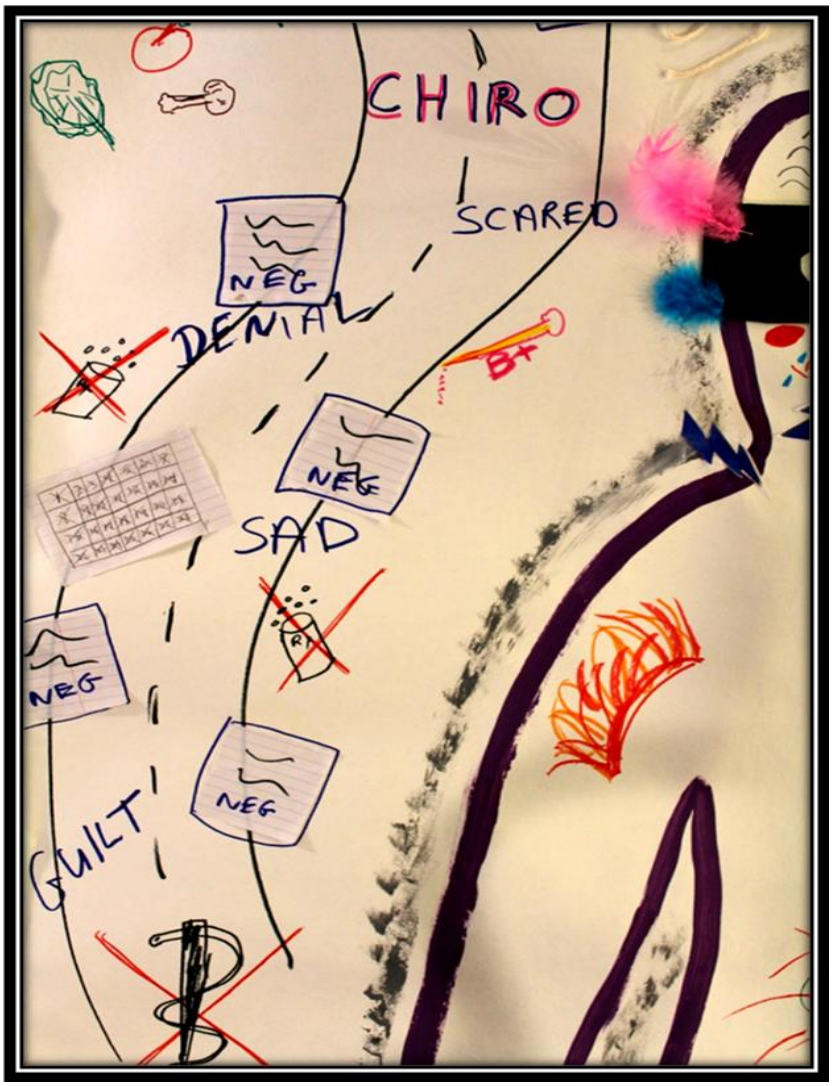


Figure 19: Anna described her healthcare journey as "a journey of conflict, it has been a journey of mistrust, not being able to trust only because there hasn't been any answers." In her body map, Anna used pages of negative tests results to represent her diagnostic journey and crossed out the caduceus to symbolize her lost faith in medical doctors.

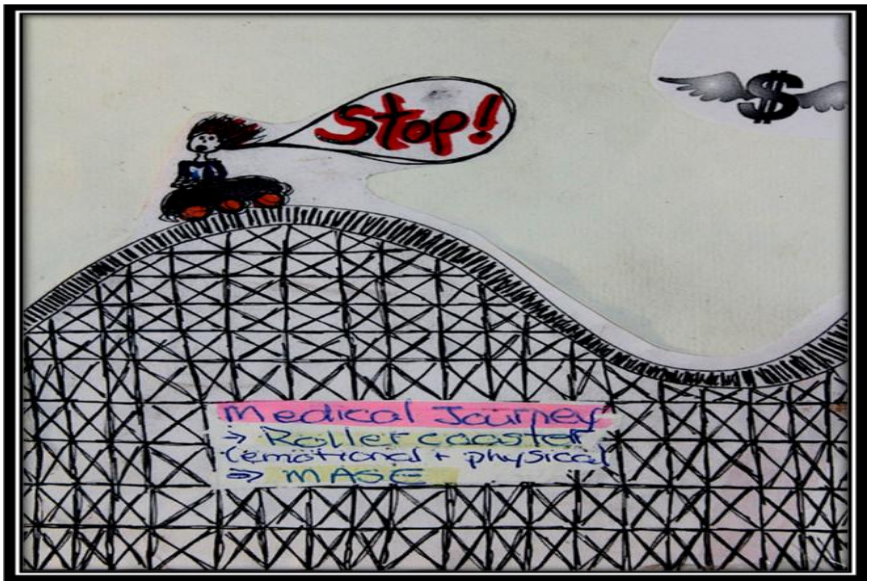


Figure 20: Darlene stated "my journey I [represented] as a roller coaster… of course money bye-bye [says in a sing-song voice] because...you lose almost everything… especially if you have to battle the insurance companies."

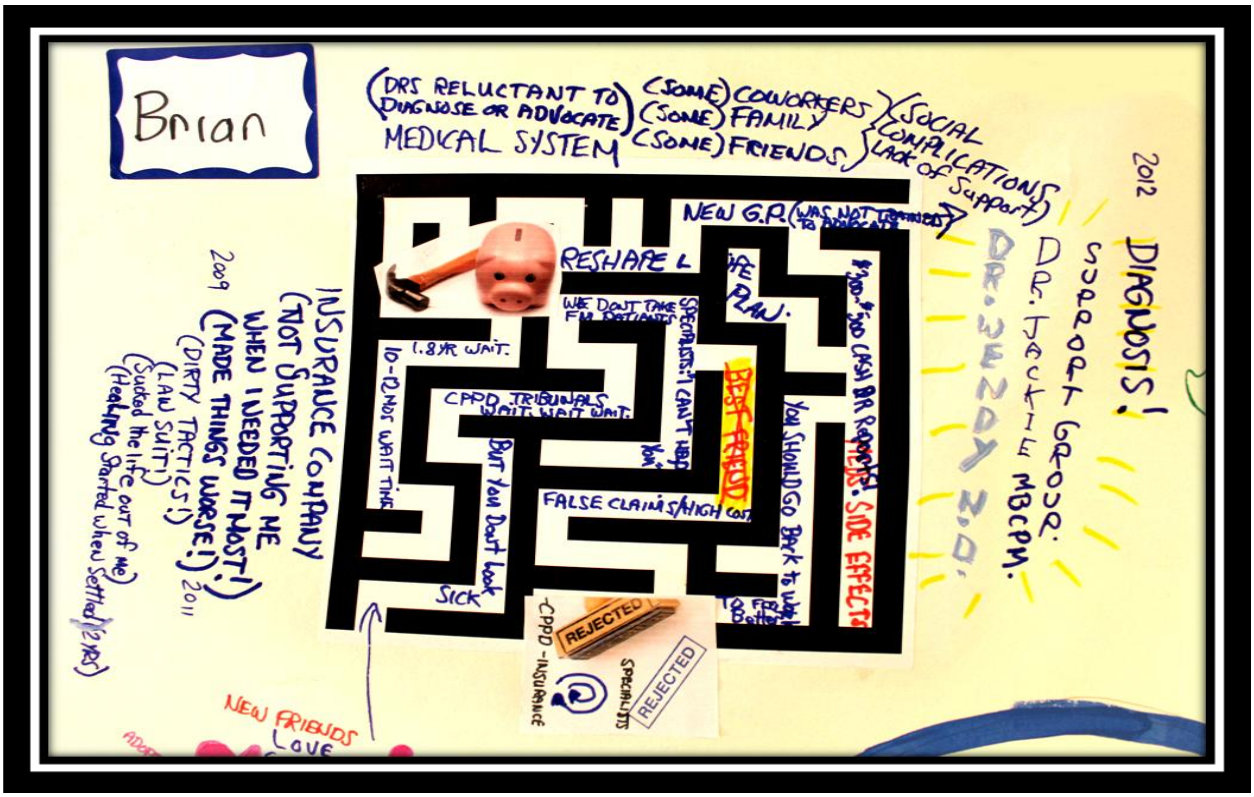


Figure 21: Brian explained that he "entered this whole medical maze."

Figure 22: Hope represented her healthcare journey as a game of snakes and ladders in which she climbs forward and then slides back. She explained how a patient lacks control in this game/journey because "you end up at one point and then the snake will go down again and you have to start all over again."

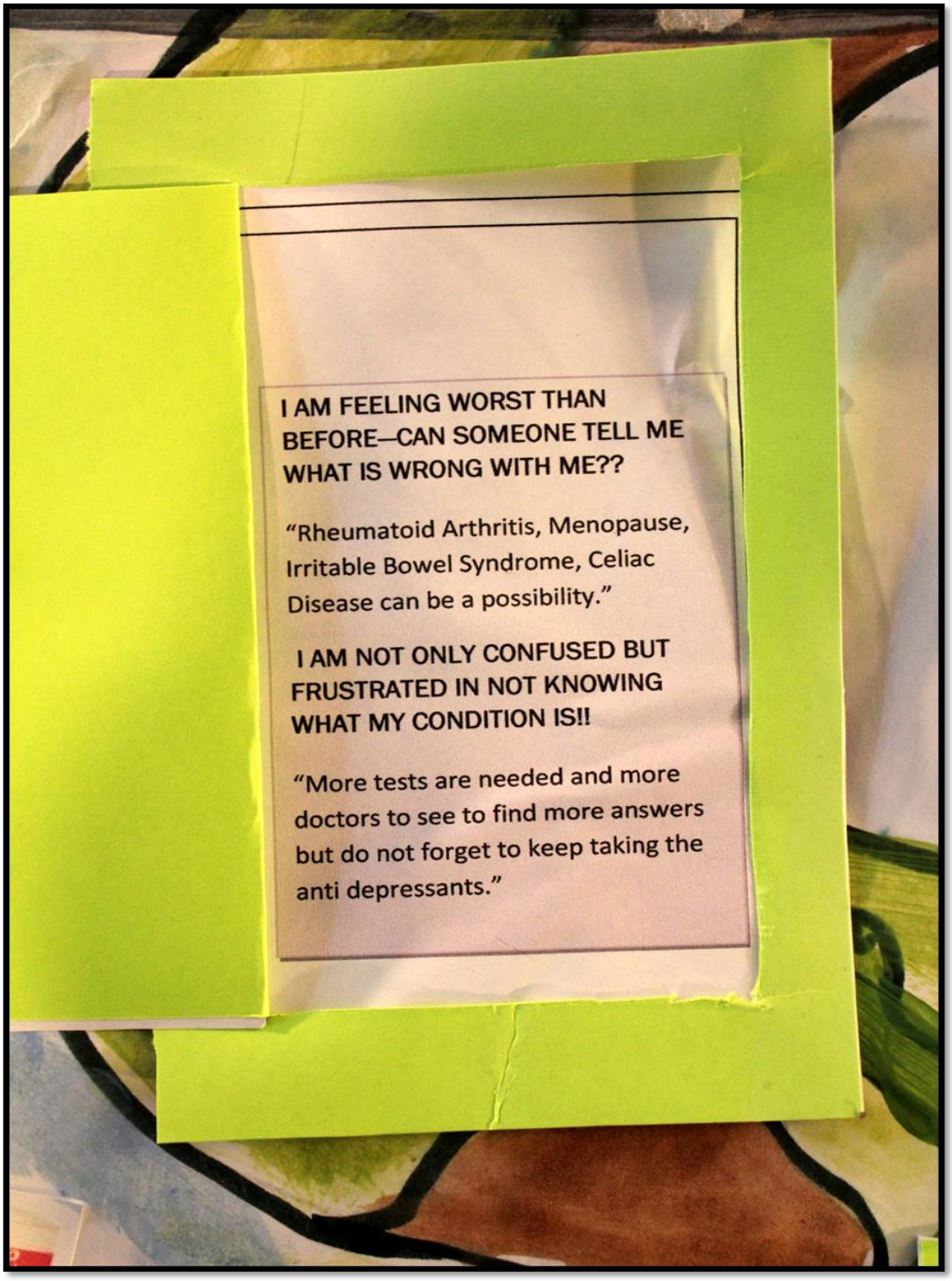


Figure 23: In her snakes and ladders game, Hope created an interactive component for audiences to open up the doors and read about her healthcare experiences.

Lack of continuity of care.

Visiting multiple providers.

Many participants not only verbally and visually represented arduous healthcare journeys, but also described that their journeys were exacerbated by a lack of continuity of care. For example, Scarbro used the term "patient prostitution" to refer to the experience of being passed around to multiple doctors.

> [T]o actually get some help you almost need…a relatively *monogamous* relationship with the doctor… And then you get some consistency of *care* and… if you imagine somebody has a *prostitution* experience and trying to go to a *relationship* experience. It's a *lifetime* of hurt to switch.

Scarbro raised the ethical issue that a patient's experience of being "passed around" to numerous doctors is harmful and demoralizing, highlighting the importance of a consistent patient-provider relationship.

Figure 24: Scarbro described a lack of continuity of care as a form of "patient prostitution."

Participants described experiencing a lack of continuity of care both across and within primary and secondary healthcare settings. Within a community health centre, for example, Snay visited multiple providers, who explained away her FM symptoms as the flu, before being referred to a rheumatologist for diagnosis.

> This is my journey with the doctors going for several months to see different either nurse practitioners or doctors in our community healthcare. It is just one centre and every time I went there I was seeing somebody different and they were always telling me that it was the flu. For months and month and months and then I finally got to see my own doctor and he sent me to a rheumatologist.

Figure 25: For months, Snay visited multiple providers in a community healthcare centre who assumed she had the flu.

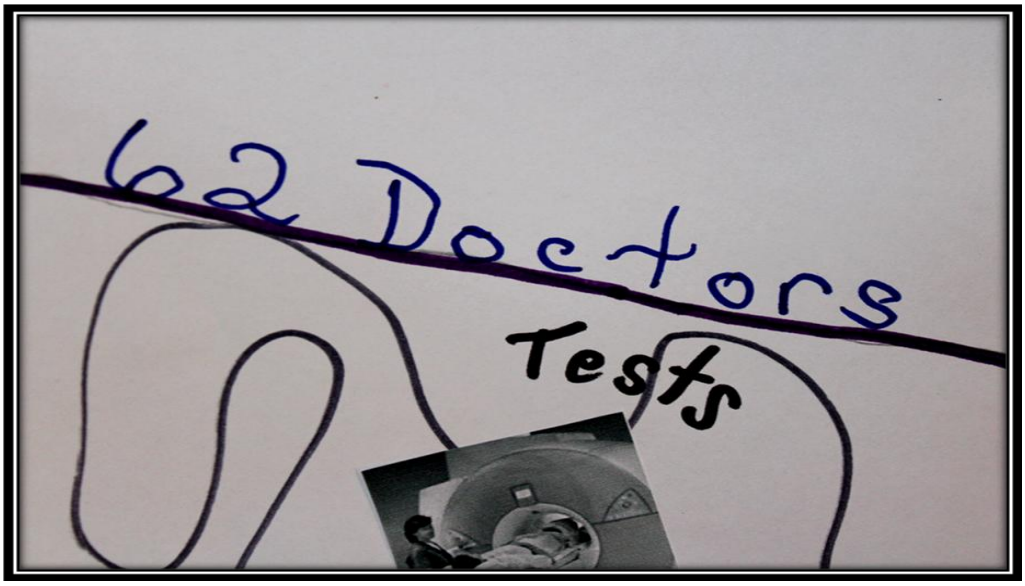


Figure 26: Penny has visited 62 doctors during her healthcare journey.

Loss of consistent providers.

Some participants reported experiencing consistent relationships with providers. However, several participants lost these relationships due to providers' changing life circumstances, including geographical moves, retirements, and deaths. These interpersonal losses were compounded by the risk of falling through the cracks due to a lack of continuity of care. Participants' reported lacking continuity of care because they were: not automatically transferred to replacement providers; expected to assume responsibility for finding new providers; unable to find available, accessible, and supportive providers; and, placed on waitlists. For example, Phoenix explained that during her year-long diagnostic process her family physician stopped practicing medicine due to cancer.

> …I lost my doctor right at that time [of diagnosis]. So I kind of got lost in the system for awhile. Um, so when I finally did find a doctor - he never knew me when I was well - so

now that he got me as sick… [he said] “I don’t think that this is wrong with you”, you know, “you need to get back to work” and I got bounced around.

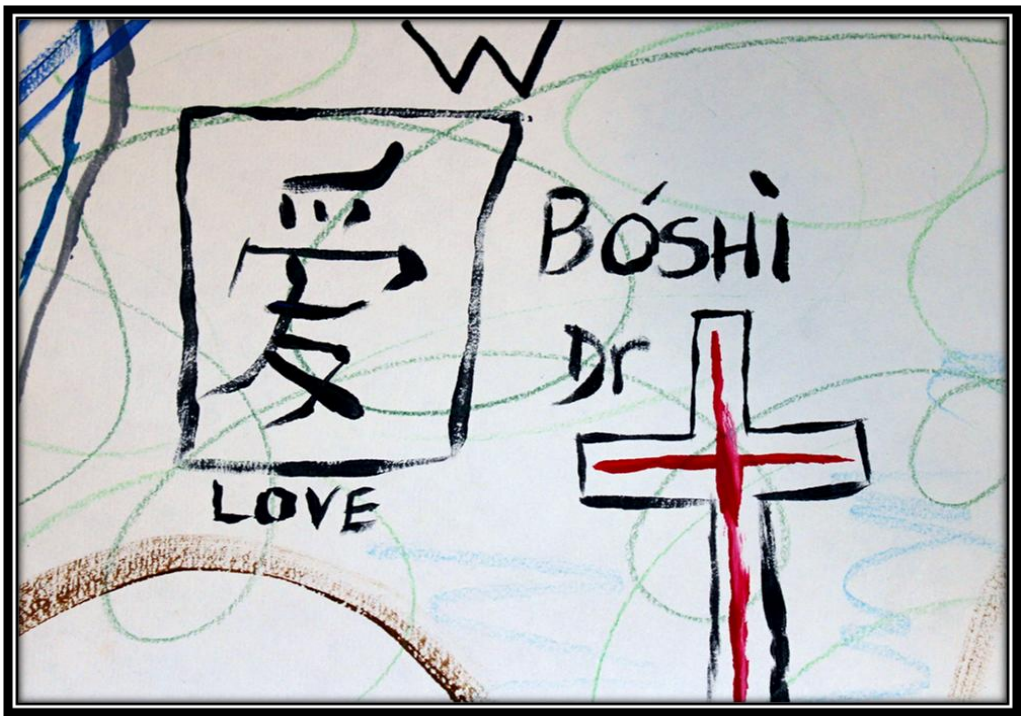


Figure 27: Phoenix drew a “Chinese symbol for love, because my doctor [name removed], I loved him. I really, really loved him and I miss him a whole lot.”

Loss of rheumatology as a designated specialty for FM.

A lack of continuity of care involved the loss not only of supportive providers, but also of rheumatology as a designated medical specialty for FM diagnosis. As discussed in chapter three, the American College of Rheumatology recently declared that FM no longer fits under the purview of rheumatology due to empirical evidence indicating that FM was a neurobiological rather than a musculoskeletal disorder (Wolfe et al., 2010). Given this change, Fanny Freckles argued that rheumatologists were “trying to dump” patients with FM out of their medical practices.

So we are going into a black hole. We don't know where we are going. It looks like at this point that we'll end up under the psychological envelope whereas I really believe it should be under the neurological but you know it is up to somebody to pick us up and not just leave us in a black hole.

Fanny Freckles highlighted the medical community's indecision as to which specialty is best suited to replace rheumatologists in FM care.

Figure 28: Fanny Freckles explained that patients with FM were being "dumped out" of rheumatology practices but not "picked up" by other specialists.

Compromised Care: Participant Descriptions of Uncaring Patient-Provider Interactions

Participants' narratives of compromised care highlighted the structural barriers pertaining to the delivery of allopathic healthcare services, as well as the interpersonal barriers within patient-provider interactions. In this study, all of the male participants and the majority of female participants reported interactions with healthcare providers that they experienced as uncaring. These participants shared common experiences despite differences in gender, age, class, culture, race, and geographical location.

Discourses of illegitimacy embedded within uncaring interactions.

Embedded within participants' reported experiences of uncaring interaction were dominant discourses about FM. The overarching or meta-discourse, which was either overtly or covertly expressed by providers, was that FM was an illegitimate condition. This discourse of illegitimacy was reinforced by two interconnected discourses about the taken-for-granted reality of illnesses and diseases. The first discourse is that physical illnesses and diseases are evident in patients' physical appearances, functional medical tests, and positive laboratory results. The second discourse is that physical illnesses and diseases that cannot be detected in patients' appearances and test results are a manifestation of mental illness. These two discourses -- based on the positivist and binary logic that visible illnesses/diseases are legitimate whereas invisible illnesses/diseases are illegitimate -- permeated uncaring interactions.

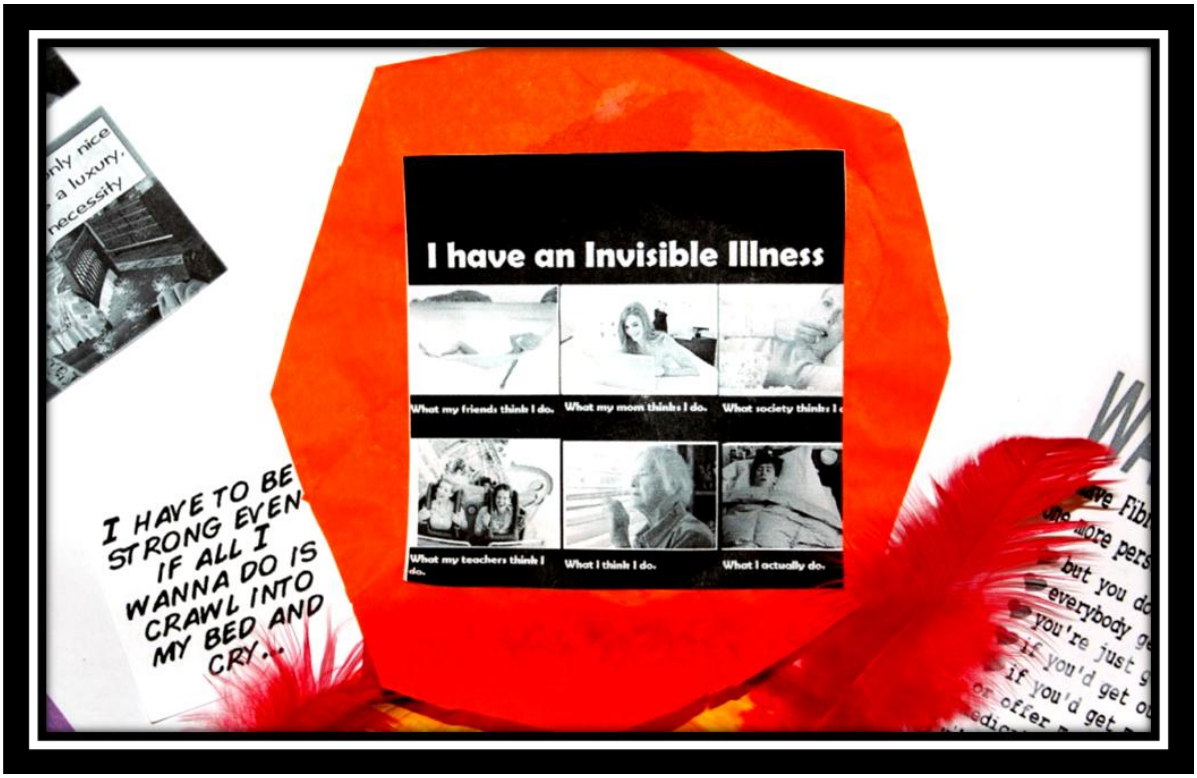


Figure 29: Penny stated, "A lot of times I feel invisible… no one actually sees who I am… at the start of this [journey] I really felt really alone because nobody knew that much about fibro…"

Figure 30: Snay depicted the discourse about FM was not a "real medical disease."

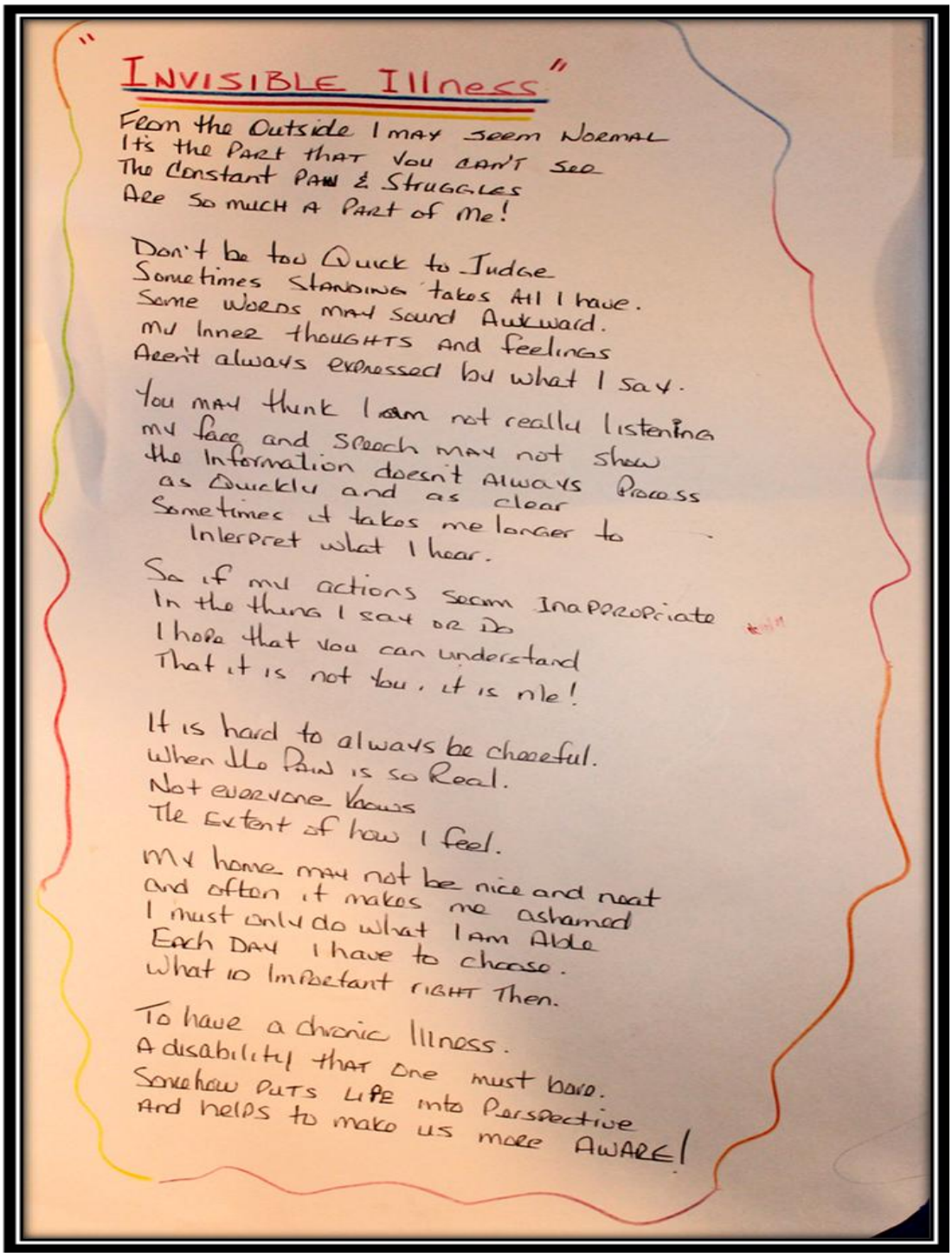


Figure 31: Snay wrote a poem, located on the left side of her body map, to express her experience of living with an "invisible illness." Snay's opening lines: "From the outside I may seem normal. It's the part that you can't see. The constant pain & struggles. Are so much a part of me!"

The discourse of objective proof.

The meta-discourse that FM is illegitimate is partly fueled by the discourse that the presence of illnesses and diseases are objectively proven by patients' appearances and test results. Many participants reported that they did not look "sick," and therefore family members, friends, employers, and healthcare providers assumed they were well. Participants' experiences of incongruence between personal reality and public perception led to feelings of invisibility. For example, Fanny Freckles explained that people "look at us and we look normal… people assume that we don't have any pain and there is nothing wrong with us." In order to address this assumption, at the top of her body map, Fanny Freckles wrote "see my pain it does exist."

Figure 32: Fanny Freckles' message to the public.

Many participants' described that living with FM meant that their illness and identities were both invisible. In their body maps, some participants illustrated invisibility with the symbol of a mask. For example, Darlene explained that she glued a mask on her body map "because we are always telling people 'yeah I'm fine.'" Similarly, Anna drew a mask to represent that people equated looking well with feeling well.

> I feel that when… you are in a group of people with fibro you can't tell that they have fibro. It is not like someone with a broken leg or someone with… arthritis who is hunched over. We look great, we look amazing… but that's not how we feel and that's the reality of this disease… it is not obvious… and that's part of the problem. The medical community as they look at you because a lot of the diagnosis is based on how you look… and they don't see anything.

Figure 33: Anna wore a mask "especially when I am at work or with my friends because if I show them how I really feel then you can't move on."

Figure 34: Stu's body armor represented his "outward appearance." He stated "most people have no idea that there is a problem and I don't advertise it. It is also my own way of dealing with trouble - is just put on as much chainmail as I can and get through things."

Figure 35: Fanny Freckles explained that her “smiling face” was a mask, which sent the message “I’m fine I’m okay.” She also left her face white “because I feel that sometimes I’m ghostly, you know, that people aren’t seeing the real me. That’s why I have the little tear drops here because you know the pain is really underneath the smile.”

Figure 36: Darlene's blank face and taped mouth symbolized that patients with FM are both invisible and silenced.

Some participants compared their invisibility to the visibility of people diagnosed with "recognized" diseases. For example, Lori discussed that people with heart disease and diabetes

were socially permitted to appear well while having their illness experiences validated because both the source and progression of their diseases were biomedically visible.

> But there is a real distinction [between recognized diseases and FM]… you can have heart disease and not look sick. But if you get diagnosed with heart disease nobody questions the necessity for you to lie down. To take it easy, to perhaps not work, to do all of the things that this enlarged heart or malfunctioning heart or the heart that is not beating properly that it requires you to do; same thing with diabetes or any of the things that are um, established enough in the medical lexicon that you know what the repercussions are, you know what the issues are … you say to anybody um, "I have heart problems" and many [say] "go take a seat." You say to somebody "I have fibromyalgia" and they say "huh?"…the not looking sick is part of it but you add that too what you got and you can't even point to a part of your body and say that "part it is inflamed" or "that's not proportioned properly." Or "my blood cells are out of whack" because nothing shows up.

The discourse of mind-body dualism.

The discourse of objective proof is connected to the discourse of mind-body dualism whereby diseases are constructed as solely existing legitimately in the body or illegitimately in the mind. The interconnection of these discourses was discussed by some participants. In a focus group session, for example, Lori and Weezie discussed the physical validity ascribed to recognized diseases.

> *Lori:* …we wouldn't be here today if we had diabetes or we had heart disease or if we had cancer or any of those. They are recognized. I mean you still can't see a lot of

them…You can't see just by looking at you that there is cancer... But there are tests that will show it. With us the tests all come back normal.

Weezie: Or if you say to someone you have cancer, they don't say it is all in your head.

Many participants described that because FM could not be located below their necks, providers assumed the condition existed in their brains and, more specifically, in their minds. For example, Hope stated, "the rheumatologist, the psychiatrist, the gynecologist, the endocrinologist… thought I was clinically depressed and that was the first thing that they did was say I'm depressed." In comparison to Hope, some participants were not only labeled as mentally ill, but also as malingerers who possessed ulterior motives. For example, Angelina experienced difficulty ambulating due to pain. She explained that the doctor not only dismissed her symptoms, but also insinuated fraudulent motives.

He said "there's no reason to limp." And I thought "wow, if you know that and you're watching me, you're watching me limp, help me to stop limping!"… I said that to him actually. And he said "well it's all psychological." And when I was discharged he said that everything I'm going through is psychological. Basically that's the reason why I'm going through it. So it's me, and I'm looking for financial gain.

Figure 37: Lori painted her hand red and black symbolizing her fury about providers' biases.

Participant experiences of providers' withholding clinical services.

The meta-discourse of illegitimacy and the accompanying discourses of objective proof and mind-body dualism were interwoven within participants' narratives about uncaring patient-provider interactions. Participants described that providers' expressed the illegitimacy of FM in a continuum of discriminatory attitudes ranging from moral judgment to paternalism, apathy to emotional abuse. This discrimination manifested in punitive medical practices, such as either threatening to withhold services or actually withholding said services. The following section reports participants' narratives of the ways in which providers' withheld assessment and diagnostic services, legitimation through diagnosis, medical appointments, services within appointments, and empathy.

Withholding access to assessment and diagnostic services.

Many participants interacted with physicians who dismissed their health concerns and subsequently withheld services for diagnosis and treatment. Regarding diagnosis, the role of family physicians has historically involved referring patients both for laboratory tests and to

medical specialists in order to rule out the presence of other illnesses and diseases. According to many participants, the stressful and time-consuming nature of the diagnostic process was compounded by physicians' reluctance or refusal to provide referrals. As gate-keepers to accessing health services, physicians' decision making processes about referrals may be impacted by their responsibility to contain costs. However, participants' experienced physicians' reluctance/refusal to provide referrals as a punitive rather than a fiscally-motivated measure. The experience of punitive gate-keeping, for example, marred Lori's healthcare journey for over three decades.

> I was probably around twenty when I first started experiencing pains… I was in the States for six months and I went to a doctor down there… he said, "there is nothing wrong with you." Not, "I don't know" but "there is nothing wrong with you." I then saw my own doctor when I got back and he took his blood tests and said "there is nothing wrong with you." Again, not, "I don't know", but "there's nothing wrong with you." Six months later I went back again because I was still exhausted and couldn't function and same blood tests, same response: "There is nothing wrong with you." This went on for years. I asked him if he could try to figure out some other testing to do. "Well, there is nothing wrong with you"… I'm sixty now so between the time I was twenty and the time I was fifty, I was getting very little help. It's been frustrating, it's made me very angry, it's made me mistrustful of the whole healthcare system.

Withholding legitimacy through diagnosis.

In the medical model the act of diagnosis is supposed to provide relief via medicalization, the classification and legitimation of disease. This was not the case for many participants whose narratives of diagnosis revealed a cycle of illegitimacy: providers withheld diagnostic services

because they considered patients' health concerns to be illegitimate and then withheld legitimation post-diagnosis due to the controversy of the FM diagnosis. These participants reported feeling that the FM label plunged them into an abyss of rejected medicalization and illegitimacy. Angelina, for example, argued that doctors diagnosed FM as a means of appeasing patients, who suffered from mysterious symptoms, without believing in the diagnosis themselves. She questioned whether doctors were "…trying to shut me up? Do you want me to go away? what are you getting from telling me I have fibromyalgia? What do you believe about it? is it something you *actually* believe?"

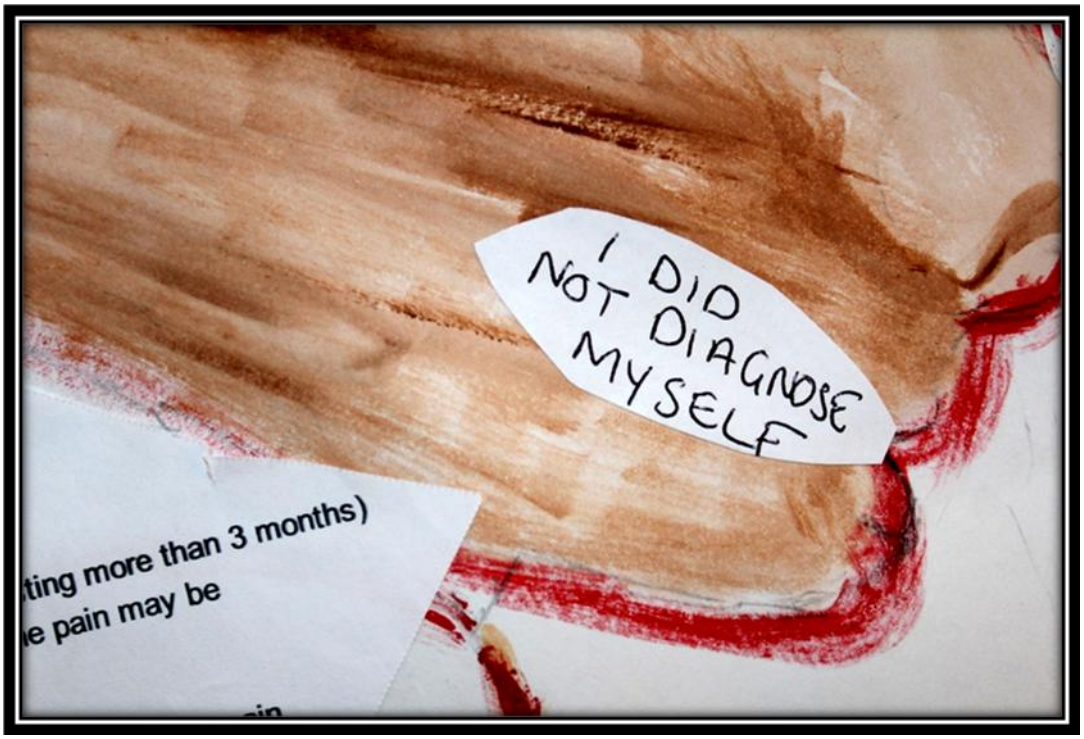


Figure 38: Angelina explained, "I didn't diagnosis myself, I just basically told you [doctor] what I was experiencing… So the fact that you diagnosed me, you *should* take into account what you've just told me because it has repercussions! It's like if you tell someone they have cancer. They're gonna go frantic..."

In this system of withheld legitimation for patients with FM, said patients were expected to omit information about their own condition. For example, Marie explained that she was instructed by a specialist to avoid disclosing her FM diagnosis to hospital doctors.

> [T]hey won't even bother seeing you. "Keep that to yourself" and I have been told that a couple of time at different places, where it's like, "don't mention this - it is not a good thing to have. Tell them everything else; do not let anybody know about this."

While some participants strategically did not disclose their diagnosis, others regretted self-disclosure to hospital doctors. For example, Angelika reported visiting the emergency department due to chest pain and waiting twelve hours for an assessment.

> I've also been to the emergency and never will go again. I'll never mention fibromyalgia because I was there at five in the evening and I didn't get out until six in the morning, only to be told go home and go rest.

Angelika's narrative is an exemplar of how emergency department wait times are partly determined by patient triaging. In this system, patients, who have chronic conditions and do not present with visibly severe symptoms, are given the lowest priority. Angelika's chronicity could partly explain why her acute symptoms were ignored. This experience taught Angelika that in the future she should neither utilize emergency services nor disclose FM because it biases care. Like Angelika, many participants raised concern that providers viewed FM as a wastebasket diagnosis to explain all symptoms, thereby placing patients at risk for delayed diagnosis and/or misdiagnosis of co-morbid conditions and even life threatening diseases. Angelika's narrative provokes the question of whether a wastebasket diagnosis transforms patients into wastebasket people.

Figure 39: Angelika described her healthcare experiences as being "in the eye of the storm." She drew a triangle to depict her twelve-hour wait time in the hospital emergency department. Above the triangle, Angelika used lightning bolts to symbolize the "doctors approach," drew a figure of herself decrying that "no one is listening," and wrote that she felt "bewildered by doctors."

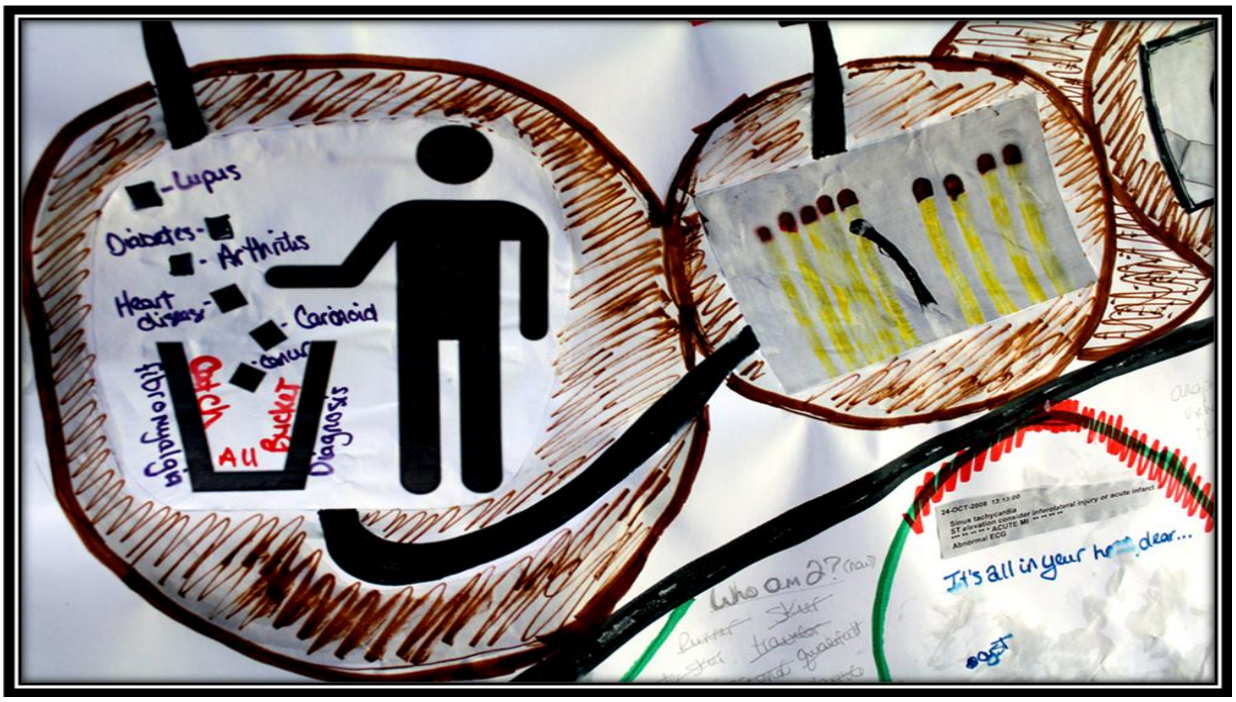


Figure 40: Sarah depicted FM as a wastebasket diagnosis.

Withholding medical appointments.

Participants recounted that providers withheld legitimation, services for assessment and diagnosis, as well as access to follow-up appointments. For a period of time, for example, Angelika booked frequent appointments with her family physician in order to assess and treat new symptoms; she did not know if these symptoms were part of FM or indicative of an undiagnosed co-morbid condition.

> I kept going to the doctor every two days and he said "if you keep coming here I'm going to put you in a crazy house."…Like to be institutionalized because he didn't want to hear anymore of my nonsense. Because he took me as crazy.

Angelika's narrative highlighted that her physician treated her as a malingering nuisance as opposed to a patient with valid physical health complaints. This appears to be an example of a

physician abusing his power by controlling the frequency of Angelika's appointments via the threat of an involuntary inpatient assessment in a psychiatric institution.

Figure 41: Angelika wrote "I am not crazy" on the top of her head.

Participants reported that providers withheld appointments not only through the threat of institutionalization, but also through the expectation that patients attend appointments alone. This expectation counters the recommendations of FM advocates that patients should bring family/friends to medical appointments to provide emotional and practical support (e.g. having friends/family take notes and ask questions is a strategy to manage FM-related memory loss). Participants who brought family/friends to appointments reported that doctors' would not proceed with these appointments unless the rule of patient-caregiver segregation was followed.

For example, Marie reported, "The rheumatologist told me that, 'you can leave your mommy in the waiting room' and I said 'no my mommy can come with me'." As a consequence of the rheumatologist's condescension, Marie reported leaving her appointment. In comparison, Sarah described that her physician prematurely ended her appointment: "My GP was incensed that I had brought my husband and kicked us out of his office." Marie and Sarah's narratives illuminate that segregation can be understood as a byproduct of the medical model's view of patients as de-contextualized, individual, "independent" organisms. In other words, in both theory and practice, patients are seen in isolation. Hence, patients who brought family/friends to appointments broke this code of conduct and were subsequently punished through paternalistic practices ranging from admonishment to appointment termination.

Withholding services within appointments.

In addition to withholding appointments, some participants reported that during appointments doctors dismissed their medically-related needs. For example, Evelyn explained that her rheumatologist "was a great doctor until I asked her to fill out paperwork for my work and she didn't want to do it even though she was getting paid for it. She still didn't want to do it." Similarly, Saint Augustine reported that his psychiatrist did not complete a report for his insurance company before leaving her hospital position for a different workplace.

> I saw her [psychiatrist] and for a few months, four months, and she had to write a report to my insurance company. She was leaving and she did not write the report. I could not get benefits because there were no reports. I found out she was working at [hospital name], I took all the forms and ran over there and I phoned her office and she said she would not fill the form out because that is not her problem anymore.

By not completing the insurance forms, the psychiatrist delayed Saint Augustine's ability to obtain financial support. Both Saint Augustine and Evelyn's examples illuminated how care is compromised when the physician's gaze does not extend beyond the body of the patient to include how the patient's body and mind are situated within social contexts.

Figure 42: Saint Augustine crossed out an image of a "doctor on duty" and wrote "sorry cannot write your [insurance] report." He also drew a hammer to represent how the provider's treatment led to feelings of "hammer crushing hope."

Withholding empathy.

Participants' examples of uncaring interactions illustrated the crime and punishment of contested conditions: the crime is to have FM and the punishment is the withholding of both healthcare services and empathy. Participants indicated that the experience of having empathy withheld involved feeling misunderstood and mistreated by providers. Participants repeatedly described their wish to be treated with kindness, warmth, respect, validation, and dignity. For example, Angelika explained "I've gone to the doctor and I've said 'look, I don't want anything from you. I just want you to understand me'. I couldn't even get that from them." Angelika's words were echoed by several participants who reported that the act of understanding is an emotionally healing intervention.

The process of understanding involves the skills patience and listening. According to many participants, these skills were missing from providers' interactions. For example, Scarbro played with the term "patient" to illustrate his observation of a double standard whereby providers acted "impatiently" while expecting patients to be "patient." Scarbro stated, "They [doctors] expect you to be patient. But the doctors are some of the most *impatient* people on earth… They're the doctor… [and] they're not patient to listen to what you're saying…"

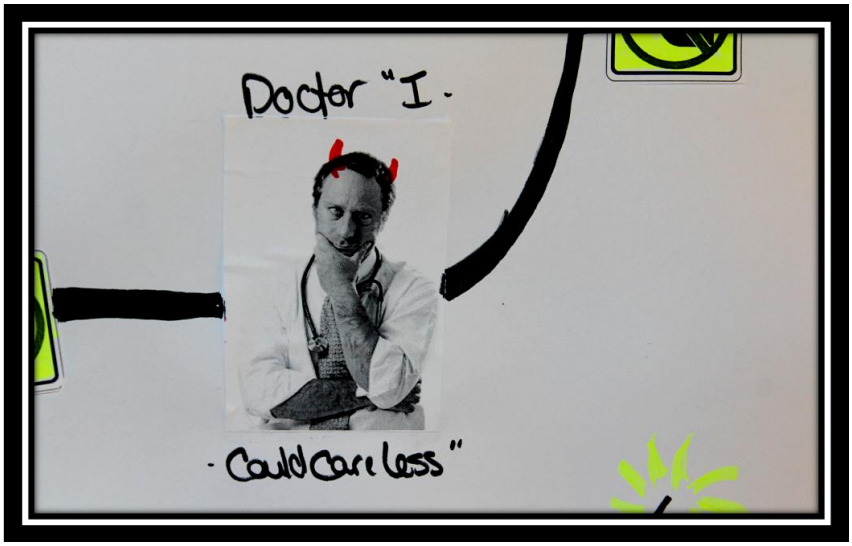


Figure 43: Sara drew devil horns on a doctor and named him "Dr. I Could Care Less."

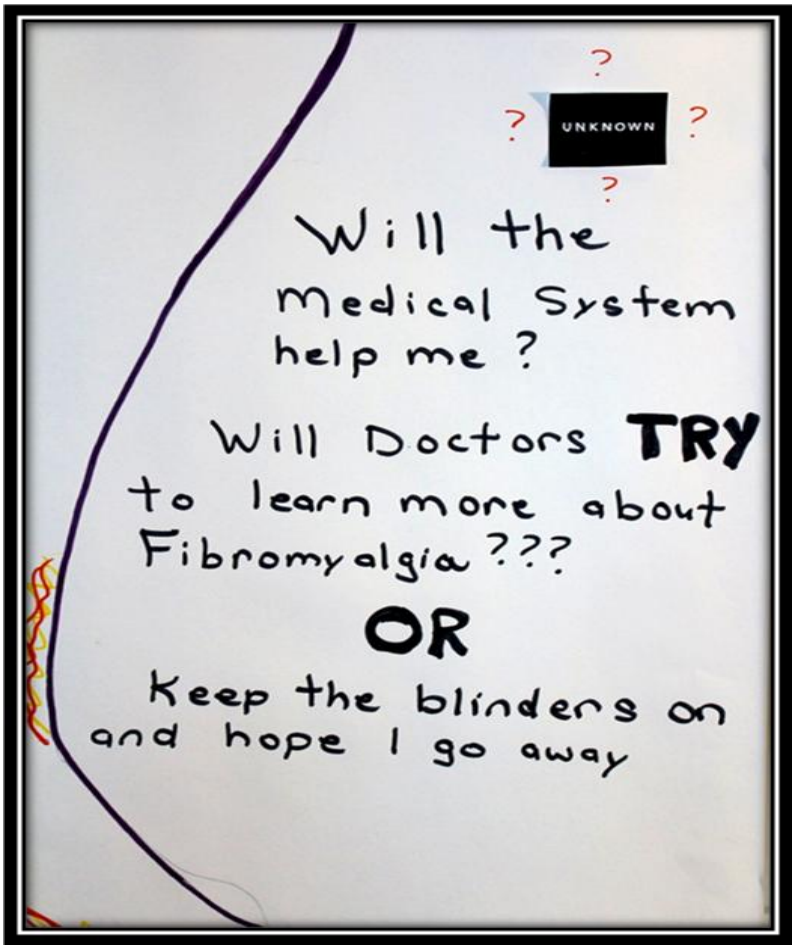


Figure 44: Penny stated, “I just want to say to doctors in the medical system: ‘Will doctors try to learn more about fibro or will they keep their blinders on and hope that we all go away?’”

The emotional trauma of uncaring patient-provider interactions.

Many participants’ narratives highlighted how uncaring patient-provider interactions were emotionally traumatic experiences whereby the stresses of navigating the healthcare system were compounded by the distress of being mistreated. Trauma was reflected in participants’ experiences of exacerbated physical and emotional pain, mortality, and doubting their own realities.

The exacerbation of physical and emotional pain.

Many participants experienced exacerbated physical and emotional pain resulting from uncaring interactions. According to Angelina, “the negative feedback [from providers] is adding insult to injury. And adds to the pain physically.” The emotional repercussions of providers’ “negative feedback” were a prominent theme in many participants’ visual and verbal narratives. For example, Angelika drew a heart on her body map to symbolize “your heart is affected because of all the disappointment and no one understands you. Nobody sees through what you are going through and not being understood is really heartbreaking.” Similarly, Evelyn discussed experiencing heartbreak, as well as a plethora of other emotions, during her healthcare journey.

> I felt like garbage. It is a life of road blocks. I found myself always crying in pain. Not just for the physical, but the emotional and psychological. I felt brokenhearted like people had just ripped me apart. I had this sinking feeling all the time. I basically wanted to stop living. I got very depressed and I was thumbs down with life and I felt like I had a lot of dark and stormy days and I was on a constant diagnostic treadmill.

Figure 45: Angelika has experienced heartbreak throughout her healthcare journey.

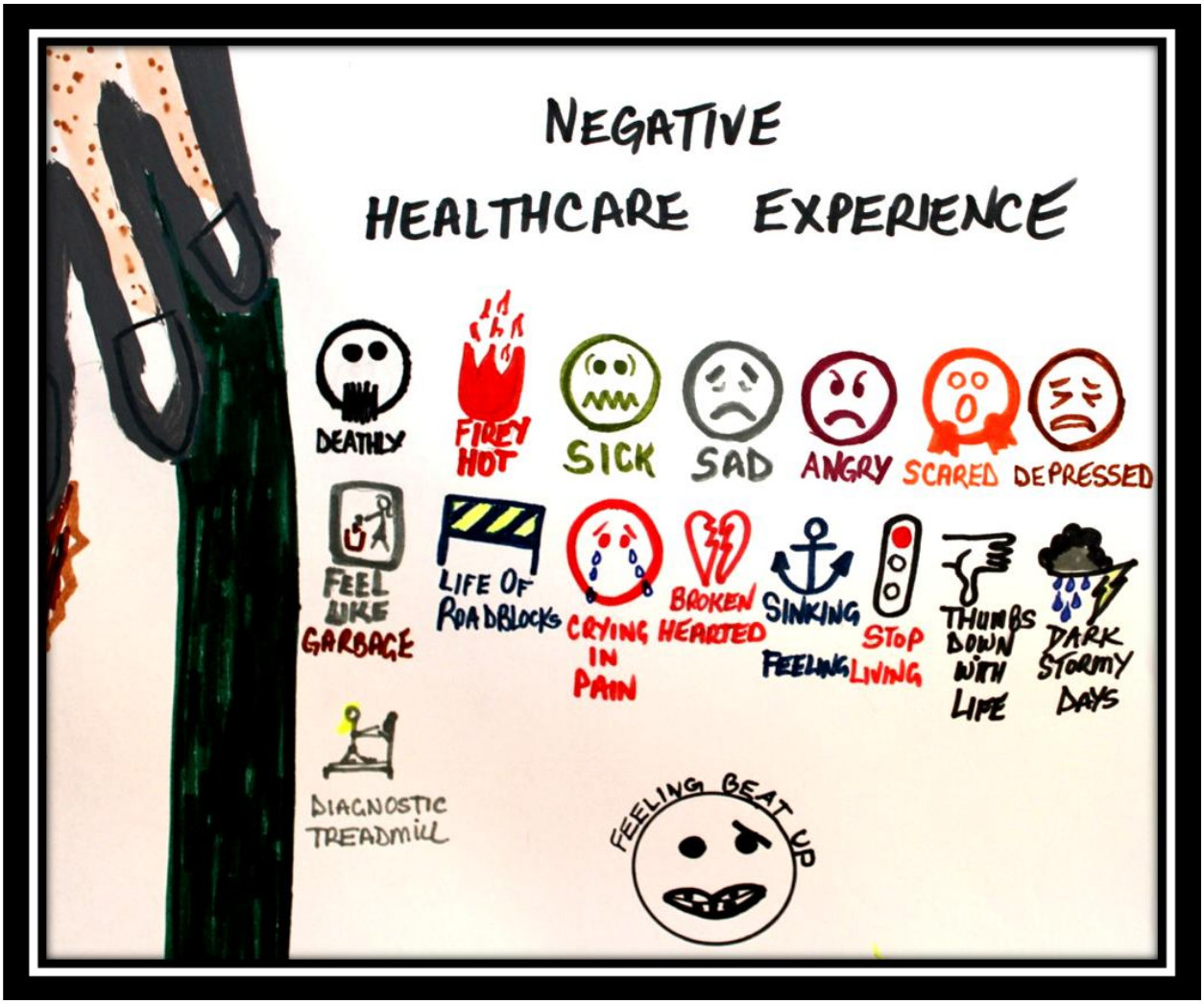


Figure 46: Evelyn described: “My negative healthcare, my little faces, deathly, fiery, hot, sick, sad, angry, scared, depressed.”

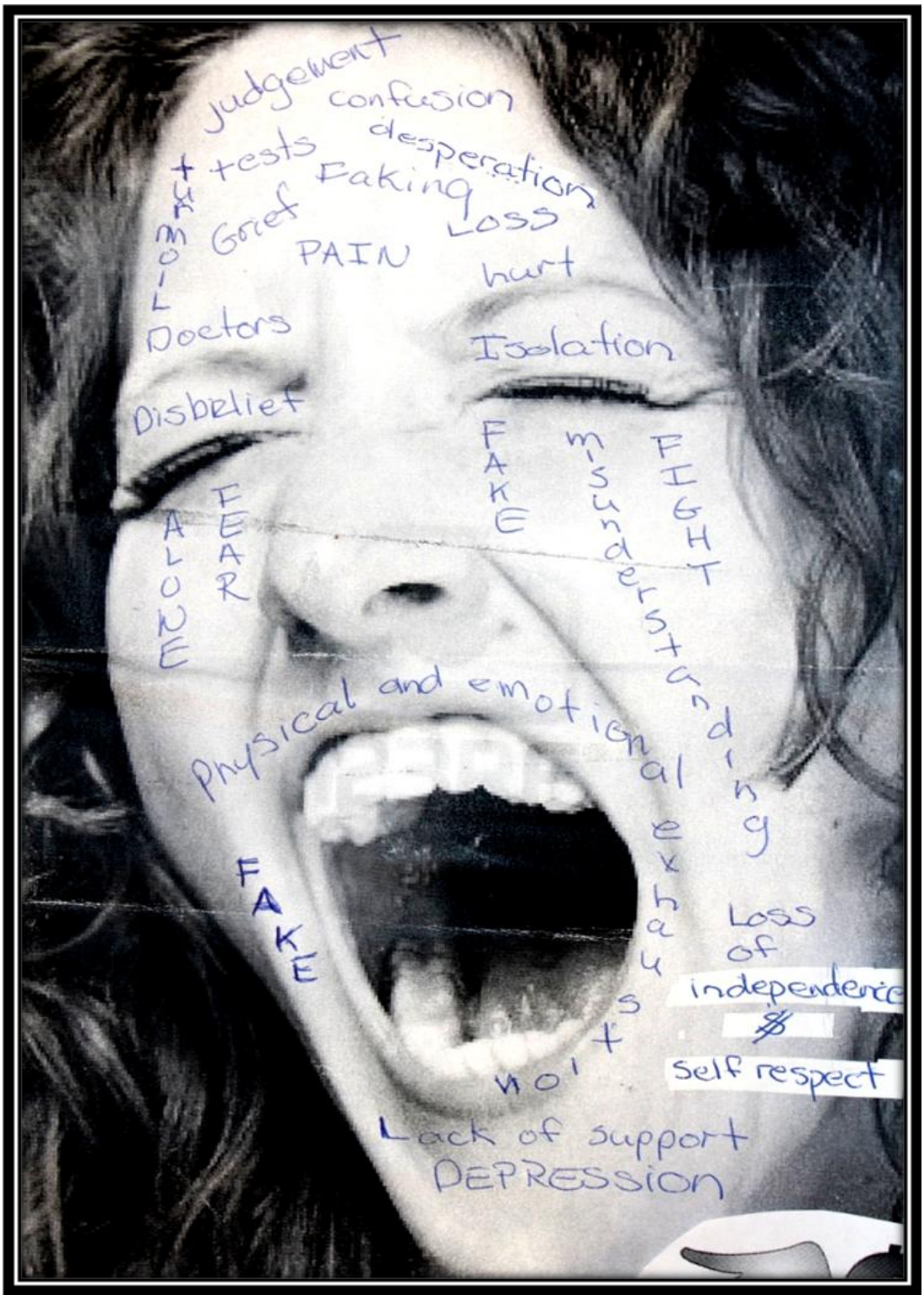


Figure 47: Darlene depicted a face of frustration.

Figure 48: Marie depicted uncaring doctors as "dark rainclouds" who tried to shower her mind with "all that negative nonsense" of discourses about the illegitimacy of FM.

Discussions of mortality.

Evelyn's wish that she could "stop living" was echoed by some participants. These participants did not disclose an imminent risk of harming themselves. However, they described current and past suicidal thoughts, as well as past suicide plans.[5] Participants explained how their suicidal ideation was an expression of hopelessness produced by living with a chronic condition labeled as illegitimate by their significant others, employers, and healthcare providers. While he was in an emotional "black hole," for example, Brian disclosed a past suicide plan, which he never carried out.

> Talk about black hole. I got so bad I got to the point where I probably – I had a plan and I was probably going to take my own life. I had it all planned out. There are only a few funny reasons why I stopped. I was worried it was going to affect my doctor, my doctor made a mistake and gave me a whole much of extra pills, he gave me a bottle of one hundred and I didn't want to get him in trouble - he was a great guy. And then I thought the first responder, the guy that is going to come and find me and I thought no, this will probably be the first time he sees a suicide, so I thought no I'm not going to do that [laughs] so anyways.

In the context of this study's findings about uncaring interactions, it is ironic that Brian's motivation for not attempting suicide was his fear of inflicting psychological harm to and emotionally traumatizing his healthcare providers. Brian's concern for the wellbeing of

[5] When participants disclosed suicidal thoughts, I ensured their safety by: utilizing my clinical social work training to assess risk; debriefing with them both in-person and via phone after each focus group session; providing resources for support services, including crisis teams and counseling; reviewing their safety plans; requesting informed consent to speak to their doctors; writing detailed notes; and, speaking to my dissertation advisors.

healthcare providers not only contrasts with but also magnifies participants' reports of the absence of concern expressed by providers in their interactions with FM patients.

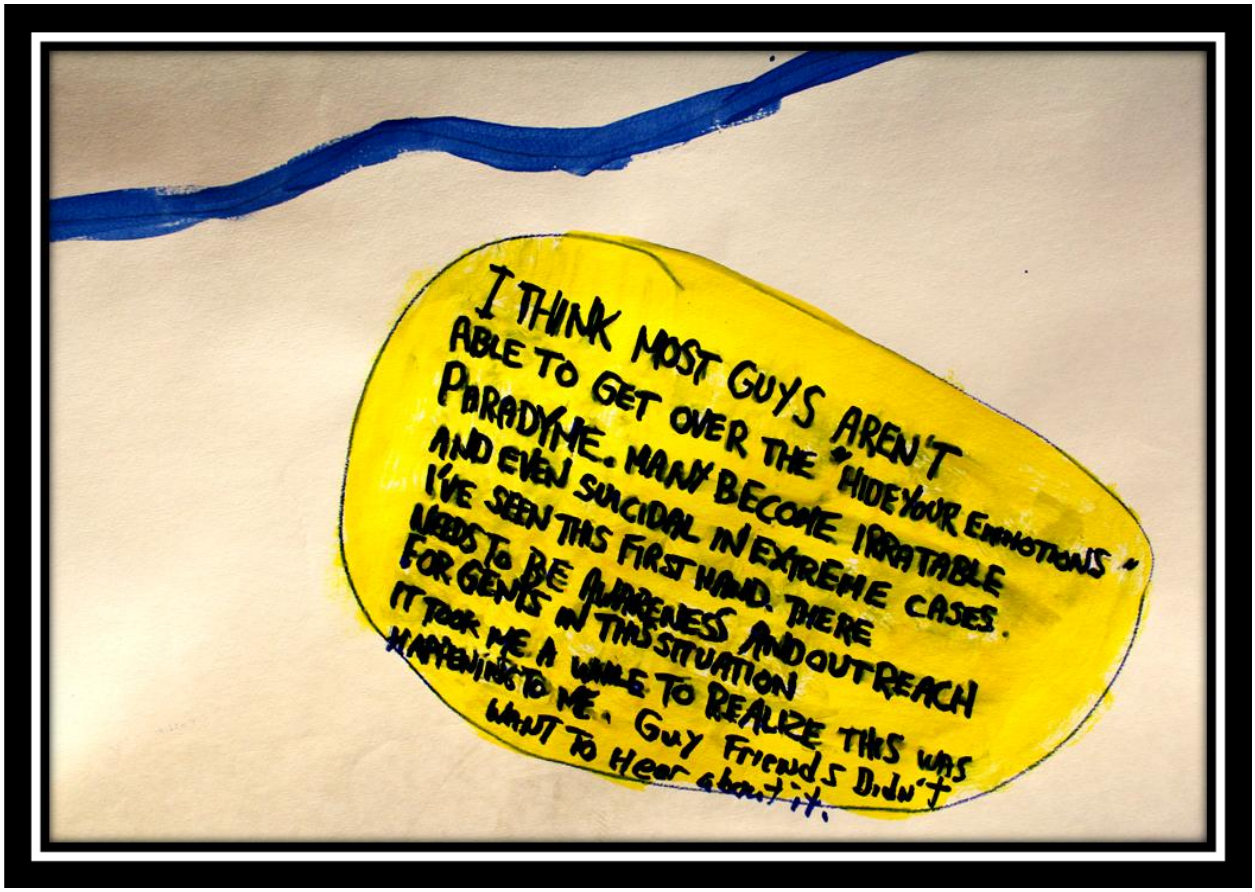


Figure 49: In his body map, Brian wrote about the unwritten gender norms of self-expression. I think most guys aren't able to get over the 'hide your emotions' paradigm. Many become irritable and even suicidal in extreme cases. I've seen this first hand. There needs to be awareness and outreach for gents in this situation. It took me a while to realize this was happening to me. Guy friends didn't want to hear about it.

Figure 50: Stu drew “a knife across my throat” and explained: “Should I or shouldn’t I? That is a daily question. And the ‘No! You Coward’ is a double entendre because which is the braver thing to do?”

Figure 51: This graphic image in Darlene's body map prompted focus group participants to disclose their own experiences of suicidal thoughts.

While some participants disclosed past wishes to die, others reported the fear that they were actually dying. Prior to receiving an FM diagnosis, for example, Phoenix felt so ill that she questioned whether she had a terminal illness.

> It was horrible. It was two things because all the symptoms I had at the time that came with my fibromyalgia were very scary. Everything was intense, um, my heart everything was going crazy all at the same time and nobody could put anything to it… nobody around me really knew what that was and my family didn't. So it was like okay, am I dying? Okay I'm not dying, well, I think I'm dying, I feel like I'm dying, I actually want to die, right. So it was all of that crazy. Um, and then you are going to these doctors and

as soon as they see the word fibromyalgia they don't want to do anything with you. So I stopped getting treatment, right.

Phoenix's narrative illuminates the compounded trauma of experiencing debilitating symptoms, simultaneously fearing and wishing for death, and being dismissed by healthcare providers.

In comparison to participants who feared they could be dying, some participants had to cope with providers' insinuations that they were dying. For example, Angelika visited her family physician to assess her head inflammation in the hopes of collaborating on symptom alleviation. However, the doctor informed her "that his best friend, another doctor's wife, passed away because she was having this similar type of thing." Angelika questioned "what are you [the doctor] trying to tell me? I'm going to die too?" In response to Angelika's narrative, two focus group participants reflected upon the meaning behind the doctor's actions.

Sarah: Well, that is abusive. It's really abusive – that is a really powerful, negative message.

Saint Augustine: Yes, I think they all [doctors] have their own fears. Honestly, look, I don't know what to do with you right now.

While Sarah thought Angelika's doctor was abusive, Saint Augustine interpreted the doctor's abuse as a projection of his frustration, fear, and helplessness resulting from the inability to effectively treat chronic illness. Regardless of the doctor's motivation, these focus group participants illuminated that providers' actions can be emotionally destructive to patients.

Gas lighting.

Participants' narratives of being dismissed by providers revealed the theme of "gas lighting." Gas lighting refers to an abusive dynamic whereby a person holding a position of power systematically dismisses another person's perspective and then provides and reinforces an

alternative (read: correct) perspective. Eventually, the person with less power begins to doubt his/her reality. Participants reported that the experience of self-doubt was a consequence of having their realities of illness repeatedly dismissed by providers. For example, Saint Augustine explained that a doctor accused him of not fasting before a blood work appointment.

> [This situation] could make you doubt yourself as a patient if you are not strong to stand up for yourself. Then you can think in your head, "did I eat something that morning?" They are building this doubt into your system and they are reinforcing it with every visit that you are not well.

In comparison, Lori explained how her physician's disbelief in FM "just eats at you."

> The tests just don't show it and so you start to doubt yourself and you start to say how can I say that I'm in pain when the doctor is saying there is nothing wrong with you?... it is the doctor as God complex… They are the ones who have all the knowledge, have all the learning so they have to be right.

Chapter Summary: Who Cares for Patients with FM?

In this chapter, I reported the study's primary finding that the majority of participants experienced compromised healthcare in the form of structural barriers and negative interactions with providers. Furthermore, many of these participants explained the ways in which uncaring patient-provider interactions were emotionally traumatic experiences. In the next chapter, I continue to report the findings about compromised care by analyzing how patient-provider interactions were shaped by participants' systems of embodied differences.

CHAPTER SIX – FINDINGS

SYSTEMS OF EMBODIED DIFFERENCES

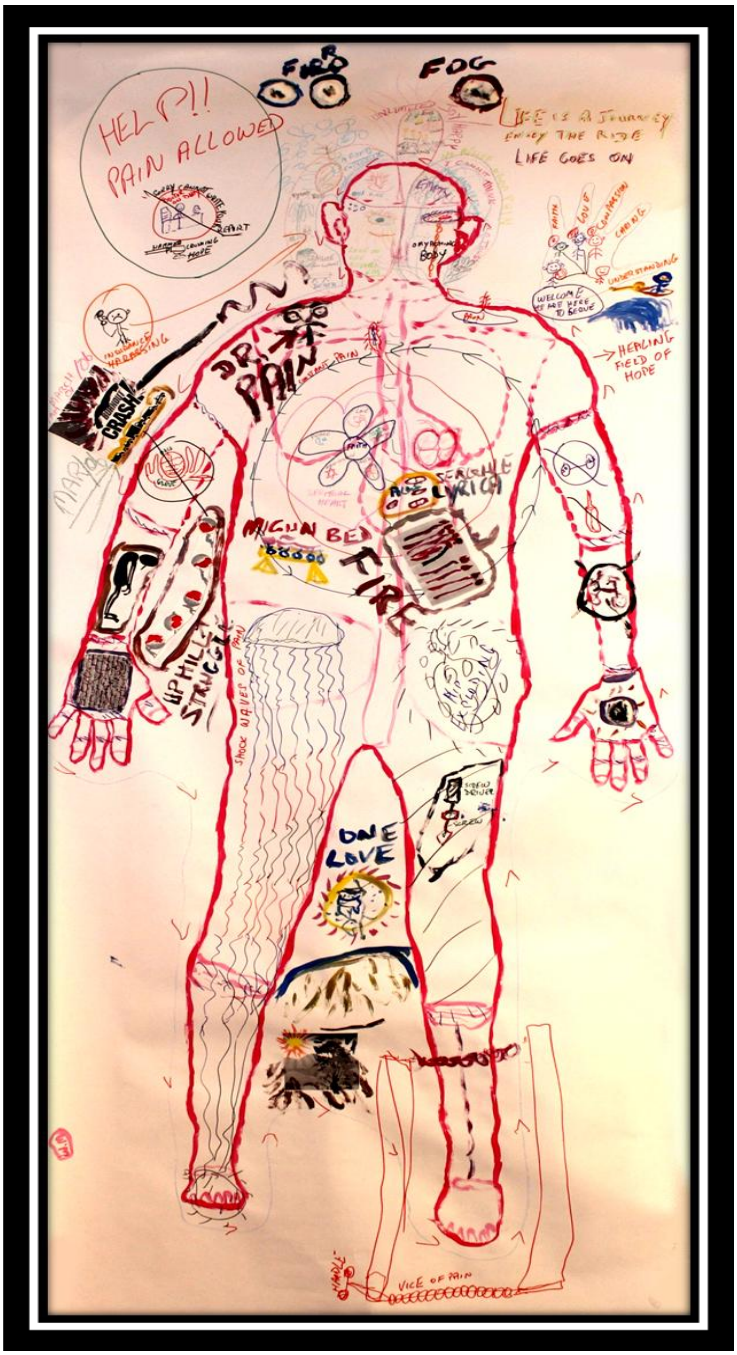


Figure 52: Saint Augustine's body map.

This chapter opens with Saint Augustine's body map because he problematized the social construction of gender. During a focus group session, for example, I asked Saint Augustine why he traced his body in bright pink, and he replied that this color symbolized spirituality and healing. By rejecting the normative assumption that the color pink typified femininity, Saint Augustine highlighted how gender can be viewed in various ways. Similarly, I found that many participants' had varied ways of viewing their gender, as well as other forms of difference. In this light, the purpose of this chapter is to examine how participants' variations of difference impacted their healthcare experiences. I accomplish this objective by first reporting the finding that participants had different views as to whether gender impacted their interactions with healthcare providers. I then report the ways in which participants described how their healthcare interactions were impacted by the interconnection of gender within systems of embodied differences, including age, marital status, family structure, trauma, class, education, culture, race, and geography.

Overview of Data Analysis Procedures and Findings

Before reporting the findings on gender and systems of embodied difference, it is helpful to first outline how these systems of difference were analyzed. I open-coded the data for themes related to participants' healthcare experiences, while simultaneously adding another layer of analysis by open-coding the data for themes of difference. Specifically, I created codes grounded in participants' identification of differences within the context of healthcare. I double and triple coded (e.g. for gender, age, and class, etc.) many transcript sections because participants' quotes revealed a cacophony of embodied differences. I then analyzed the data across codes to identify

what types of differences intersected, as well as how, when, where and to whom did these intersections occur. I found that differences intersected in a multitude of ways.

This study's research question inquired about men and women's healthcare interactions in order to compare experiences both across and within the construct of gender. Initially, I expected that gender would be a key difference within participants' healthcare experiences. During the focus group sessions, I found that some participants initiated discussions about their experiences of gender within healthcare interactions. However, other participants did not discuss gender unless I directly asked questions about this topic. Many male and female participants either did not consider gender to be an influence or identified other systems of embodied difference (e.g. age, class, and trauma) as more significant factors within their healthcare interactions. Interestingly, even when participants described differences other than gender, gender was often a covert theme within these narratives. This finding highlights that gender is situated within broader systems of embodied differences.

Gender Identity, Roles, and Relations

Perspectives about Healthcare Providers

Care was impacted by differences in "decency" and understanding.

Several participants described that their gender and/or the gender of providers did not influence their healthcare interactions. For example, Angelika acknowledged that sexism existed in the healthcare field. However, she experienced that providers' attributes such as kindness and decency were more important than gender in shaping the quality of patient-provider interactions.

> [M]y experience has shifted over the years because now I find that you just get people [providers] who are jerks, and they will treat you that way, so they will just find a reason… so you do have sexism, but generally you will find that those kind of people –

just find someone [a patient] they want to target and they will just find whatever [reason for blame] they want. So I think almost - the gender piece, my experience after years of that is that it is not so relevant. It is whether that person is a decent person or not.

In comparison, in a different focus group, a participant explained that her healthcare was compromised not because of gender but because providers lacked understanding about FM.

Hope: … I know at one point Michelle [researcher] was asking about gender. Did it matter if you were a female or did it not?

Moira: …I got sick when I was sixteen so it was never [about] hormones. It's never been about gender. No it's been more about lack of um, just lack of understanding and lack of knowledge and the medical system doesn't know what to do with us. They don't understand the illness…

Both Angelika and Moira's narratives highlighted that rather than gender, providers' understanding (or lack thereof) was a key difference that shaped their healthcare interactions.

Different gender, different quality of care.

Some participants did not find that the gender of patients or providers impacted care whereas others associated differences in providers' gender with different standards of care. For example, Scarbro explained that the healthcare system was comprised of gendered fields. Through his healthcare experiences, Scarbro observed that more women than men worked in the fields of CAM. He thought that these fields were gendered not only by the ratio of male to female providers, but also by the characteristics of these providers. Specifically, he experienced female providers working in CAM to be kinder and more empathetic than male providers who practiced allopathic medicine.

> [A]ll the restoration stuff [meaning CAM] it's actually exceptionally women-based. And it's predominately their field. All the places I have rejections and problems with are really male-based [allopathic medical services]. And they're really emotionally detached places of medical…healthcare dispension. And that's what it really is. It's *medical healthcare dispension*…. It's not like…empathetic healthcare that the naturopathic college would do… And I think that's a big difference… there's a big gender issue there. In that field. Considering that…you know what? Maybe…80 to 90 percent, 80 percent are generally women… There *are* a few good men [who provided healthcare]. And they are the ones who made the difference [in his healthcare experiences].

Scarbro described the differences among CAM and allopathic fields in terms of gender identities; naturopathy was a feminized field that provided "empathetic healthcare" whereas allopathic medicine was a masculine field that provided "emotionally detached" care. The term "healthcare dispension" evokes an image of services being provided in a mechanized, rational, and impersonal manner: a conveyor belt of care.

Hope reported similar perceptions about the gendered characteristics of providers. During a focus group session, Hope and I discussed her experience of a female family physician being more understanding and relational than a male medical specialist.

> *Hope:* If you have a female caregiver, maybe they will be a little more sympathetic than maybe if you have a male caregiver.
>
> *Researcher:* Has that been your experience?
>
> *Hope:* I have a family doctor, she sent me to a male internist and he was very skeptical.
>
> *Researcher:* Mhmm.

Hope: He was asking a lot of questions and I said "fine I'll answer whatever you ask"… Then I had to go back to him many, many times because… I could feel he doesn't want to take responsibility so that's why he's been sending me to a lot of other specialists so that he can say "based on this, this, and this I can confidently say she has this."

Researcher: Okay.

Hope: Even after he diagnosed me he said "I still want a second opinion." Whereas when my family doctor saw me… [the family doctor stated] "I understand how you feel." Right away she said that.

Hope's female physician expressed empathy by stating "I understand how you feel." This expression of empathy provided Hope with a sense of validation and legitimacy. In contrast, Hope felt that her male specialist delegitimized her condition through being "very skeptical" and wanting the due diligence of a "second opinion." On one hand, the specialist's request for a second opinion could reflect the clinical murkiness of diagnosing FM. On the other hand, the specialist's request appeared to lack compassion displayed in Hope's interactions with her family physician.

Some participants compared male and female providers' different styles of relating to patients while others discussed gender differences between male providers and female patients. For example, Angelina observed that some older, male doctors -- who treated patients with Multiple Sclerosis before the condition was considered legitimate -- possessed "old school" perspectives; these providers "frowned upon" female patients suffering from contested conditions, assuming they were histrionic. In Angelina's narrative, some male doctors possessed biased views of female patients who embodied conditions associated with the stereotypes of

feminine fragility and instability. This narrative also highlighted the power imbalance between doctors and patients due to the intersecting differences of gender, age, and professional status.

Participants' Perspectives about their own Gender

In addition to the gender of providers, some participants identified the ways in which their own gender roles and identities impacted their interactions with providers. In his body map, for instance, Stu depicted the theme of cowardice by drawing the images of a lion and a yellow heart and by writing the word "coward." When presenting his body map to focus group participants, Stu's theme of cowardice sparked a discussion about gender identity.

> *Sarah*: So do you feel like when you go – when you try to go for help, you are labeled as a coward?
>
> *Stu*: No. It is more of an internal thing. Externally, I don't think many people –
>
> *Sarah*: I imagine a lot of men carry that into offices with them, which is why they don't talk about a lot of this stuff.
>
> *Stu:* But I do, I don't know –
>
> *Sarah*: No I meant like – sorry do you carry it in or do you talk about it?
>
> *Stu*: Um, I'm pretty forthright with my doctors. I say "give me the help, if not I'm screwed. Do what you can."
>
> *Sarah*: Do you think a lot of men carry that same feeling though?
>
> *Stu:* Sure, you won't express your own weakness. I've been in the business world for years and I did a MBA and you would never admit your – one of the primary things in business is – was actually exposing my weaknesses during training sessions to executives and most business people went "what the hell is this guy talking about? You are not a human being you are a business man."

In this dialogue, Sarah questioned whether Stu was emasculated and labeled as a coward by asking for help, and thereby defying the expectation that men should suffer in silence. However, Stu articulated his feelings of cowardice as an "internal thing" whereas externally he was "forthright" in his ability to ask providers for help. Stu resisted typified masculine behaviors by "exposing my weaknesses" in the realms of healthcare and business. Stu exposed his self-proclaimed "weaknesses" in visual representations of lions, tears, and carrying the world on his shoulders; these representations evoke feelings of fear, inadequacy, sadness, lost power, and stress. At the same time, Stu depicted himself as a soldier or knight encased in body armor, a traditionally masculine embodiment of self-protection. Stu's body map magnified his struggle to reject norms of masculine identity while simultaneously displaying the internalized, gendered need to appear strong.

Figure 53: Stu represented himself as tearful and burdened by the weight of the world. He explained, "This is like a broken heart, a wounded heart. It started out as yellow. It was an armored knight with a yellow heart which is a coward, if anyone knows a yellow heart…"

Situating Gender within Systems of Embodied Differences

Systems of Gender, Age, Marital Status, and Family Structure

While some participants solely discussed gender, many others situated gender within systems of embodied differences, such as age and marital status. A key theme reported by female participants was that providers misinterpreted their pain and fatigue as symptoms of stressful life

transitions including: getting married, remarried, or divorced; giving birth; and, raising children as single parents. For example, Fran explained that her doctor was "patronizing me, saying I'm a new bride, not being able to, you know, cope with everything that was going on around me..." In comparison, Weezie reported that her doctor considered FM to be a manifestation of the stresses of remarriage and becoming an "older mother."

> I went to the doctor, had all the tests… and they kept saying, "well you know you are an older mother and this is challenging"… I thought I'm either mentally insane or I'm making this up but I didn't ever really believe I was making it up… everybody was pointing to the fact that it was a second marriage, second baby.

Fran and Weezie's respective examples of being a "new bride" and an "older mother" highlighted the embodied intersection of gender roles and age, as well as the covertly heterosexist discourse that women are vulnerable to stress. In comparison, some participants reported that providers made overt assumptions about gender and mental illness. For example, Hope stated that her doctors concluded "you are a single mom, and you are overwhelmed by taking care of your children, therefore you must be depressed."

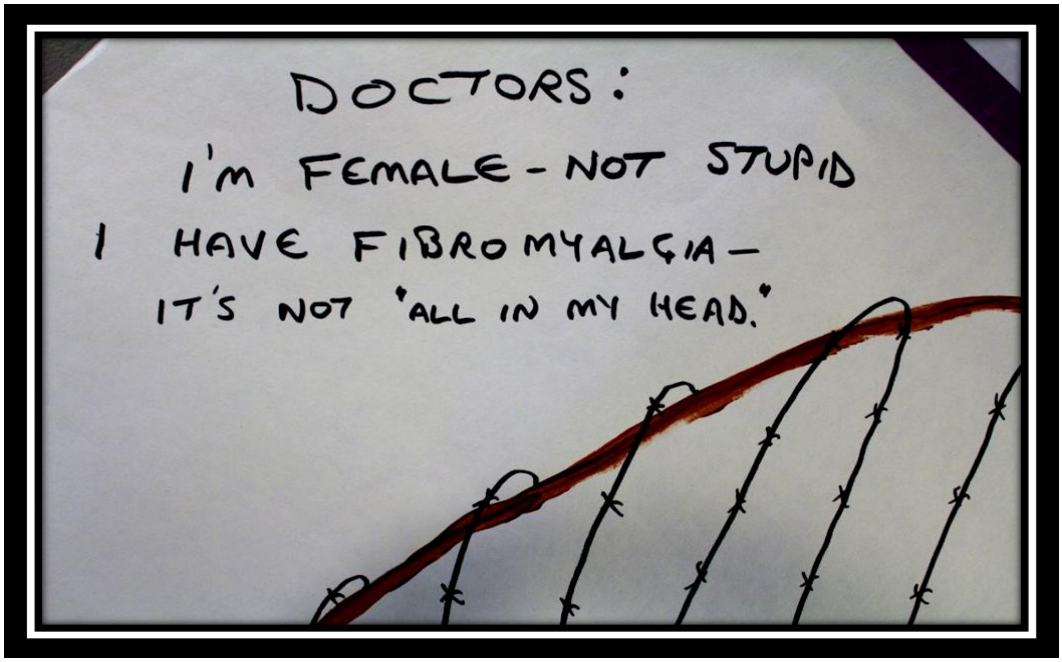


Figure 54: Lori's message to doctors was, "I'm female – not stupid. I have fibromyalgia – it's not 'all in my head.'"

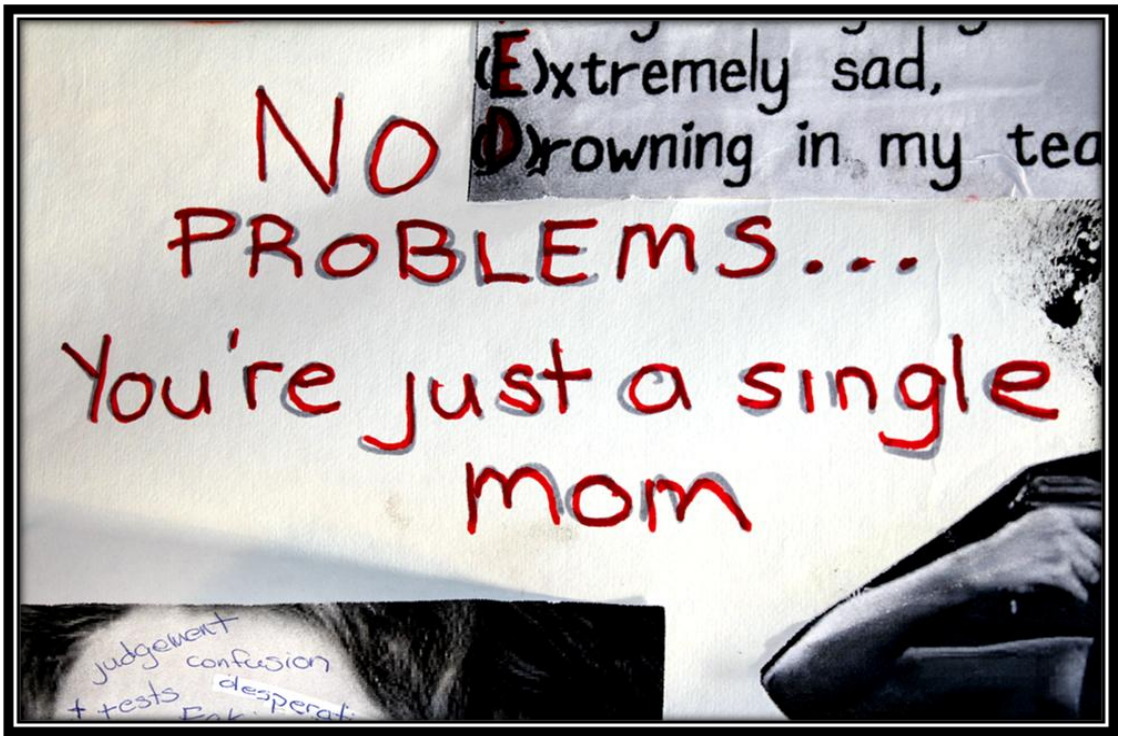
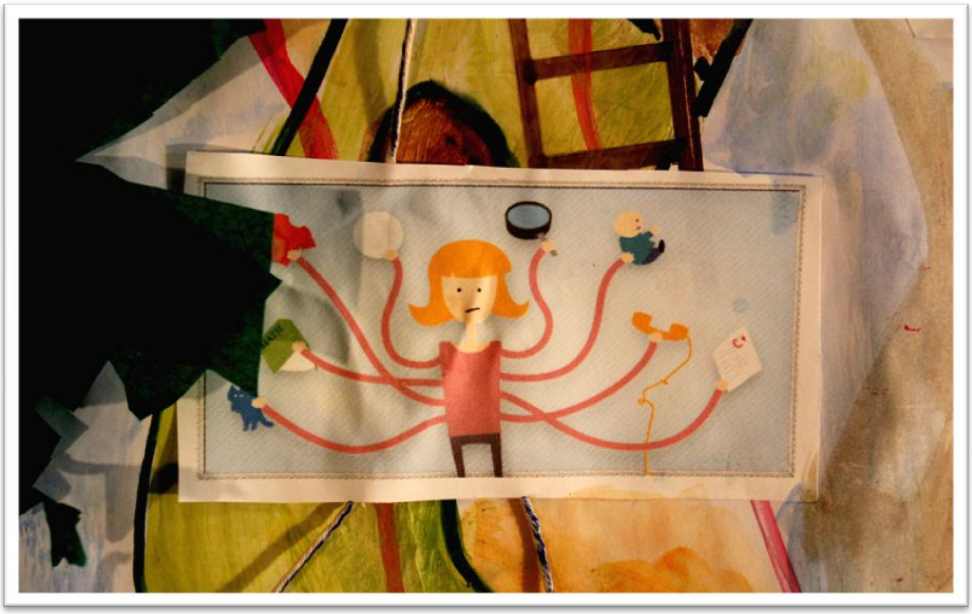


Figure 55: Darlene stated, "All I ever heard was well 'you are a single mom, so you are stressed out'. Because my daughter was extreme ADHD, they'd say 'well you are stressed over that'… I was never taken seriously."



Figures 56-57: Because of FM, Hope could no longer manage multiple roles. She explained "…I am the bread-winner, also the chauffer, I picked the kids up, I was a chef on demand. I am a multi-tasker, a friend, a networker, everything basically says how it is and now I can't do it."

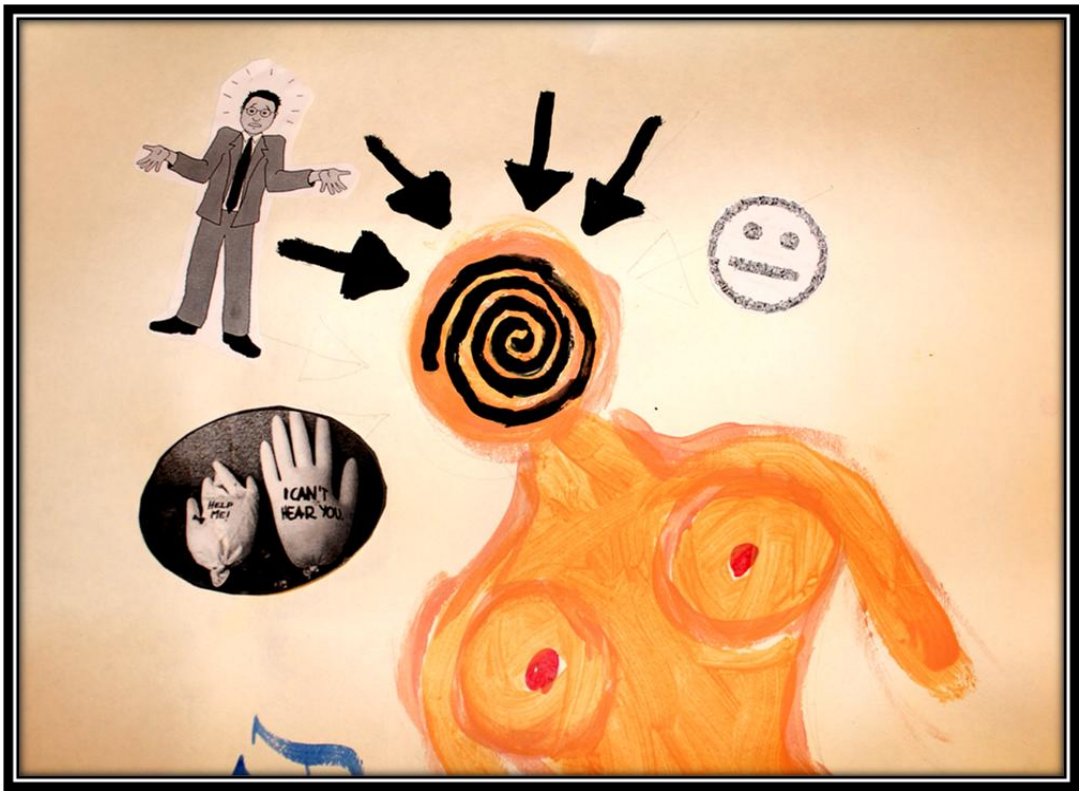


Figure 58: Fran depicted a doctor shrugging his hands and pointing to a faceless and large-breasted patient. Below the doctor is the image of two hands; the left hand is a deflated patient saying "help me" while the right hand is a hot-aired doctor taunting, "I can't hear you."

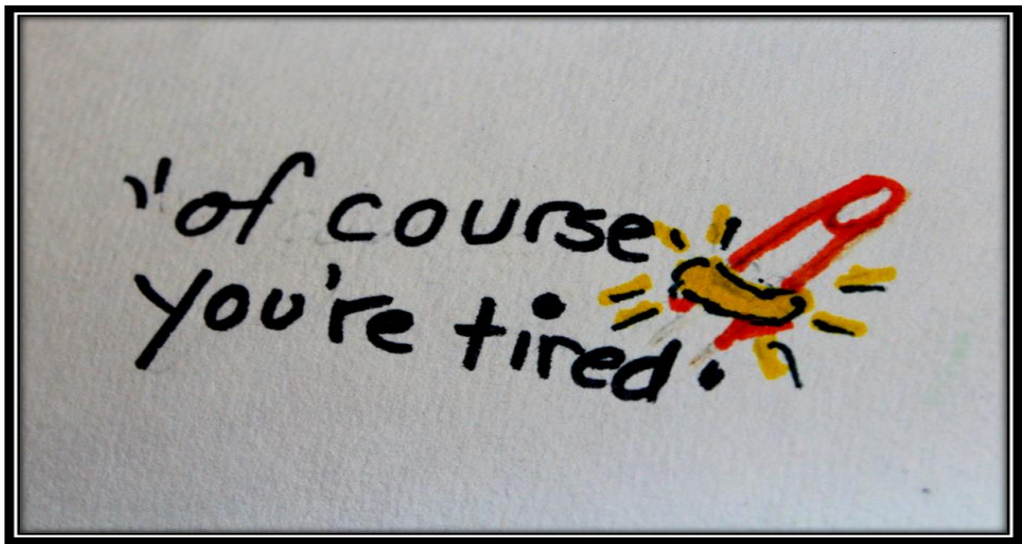


Figure 59: Fran's doctor explained away her FM as a symptom of being a "tired" new bride.

Hope's example of single parenthood magnified the ways in which values about family structure, as well as accompanying assumptions about class, impacted providers' attitudes towards patients. A similar point was raised by Scarbro who thought that being a son living with a "stable family" -- which he defined as a middle-class, two-parent household -- contributed to more favorable treatment by healthcare providers.

The coveted discourse of the "stable family" conveys an image of support. However, the image of support was viewed positively by providers as long as patients remained individuals without family accompaniment in medical appointments. For example, Marie lived with her parents and brought her mother to medical appointments.

> A lot of the times when I go to medical appointments my mom will come with me because she is just very concerned and this is my way of letting her feel a bit better about it because she always has questions that I don't think of asking… so I think they [doctors] look and think "oh, she has to have her mommy come with her" and so that does I think create a bit of a mental barrier…

Marie's narrative of bringing her mother to medical appointments highlighted the intersection of her family structure, gender role as a daughter, and age. At age 31, Marie was one of the youngest participants in the study. She reported experiencing both her chronological age and youthful appearance as barriers to treatment, stating that doctors "don't take me as seriously… I look a lot younger than what I really am."

Marie was one of several participants who experienced the onset of FM during adolescence. Participants' narratives of early onset contradicted the stereotype that FM usually afflicts middle aged women and magnified the ways in which chronic illness impacted people differently based on their life stage. For example, several of the younger participants described

that FM not only interrupted their education but also required them to either modify or completely change their educational plans and expectations regarding future employment.

Figure 60: Marie drew the number 13 in a crackled head to signify when she began suffering from migraines. She explained, “I was young too, I was only thirteen… I’m almost convinced that there is a connection between when I had my appendix taken out and when I started suffering from migraines.”

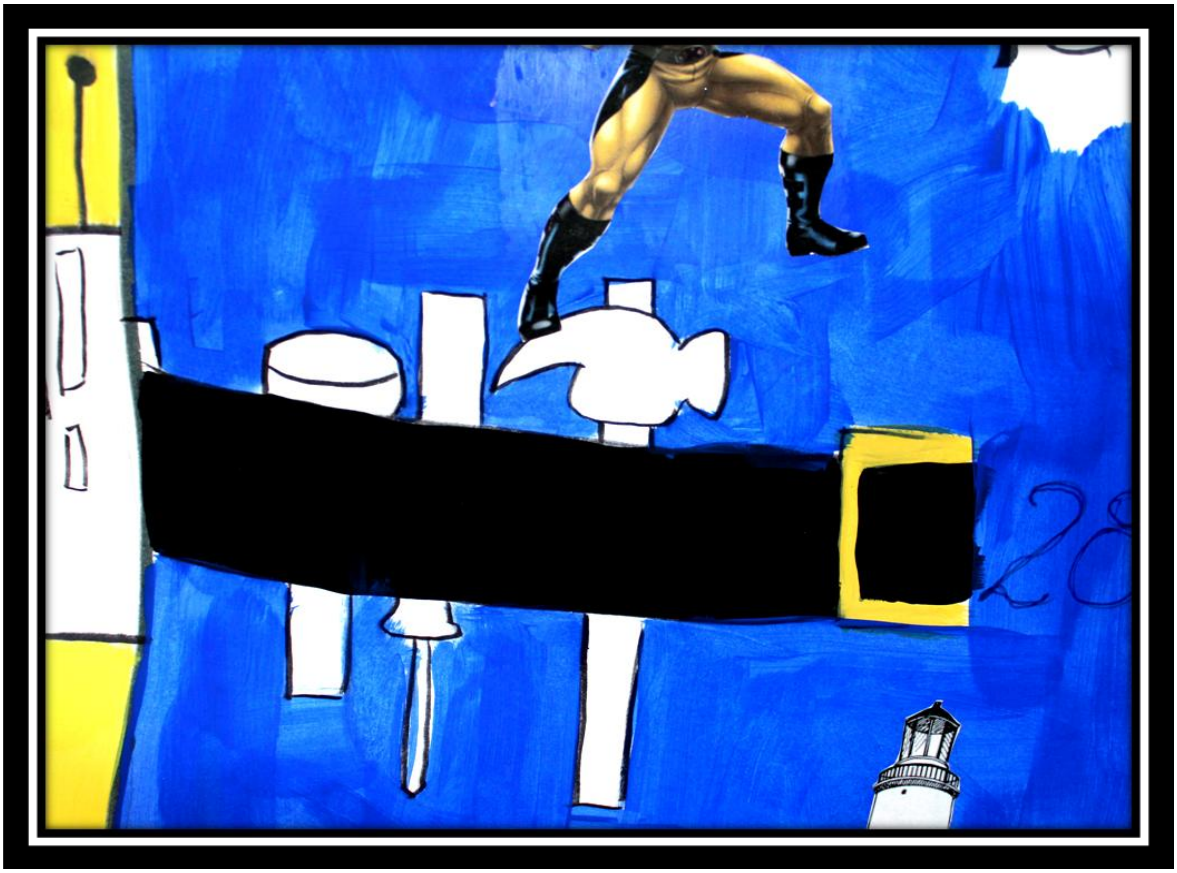


Figure 61: Marie stated, “I’m really short and female, but I’ve always been in male dominated fields”. As a result of illness, at 24, Marie was fired. “I’m almost 32 and I’ve never really had a career because I’ve been sick during the entire time that you would have been starting that.”

Systems of Gender, Age, Trauma, and Class

Systems of gender, age, and trauma intersected in the narratives of several male and female participants who disclosed histories of childhood abuse. For example, Sarah identified trauma as an embodied difference, explaining that as “a child abuse survivor… there is massive stigma… you always get pushed into the mental health [field] when there are other issues.” Sarah reported that once she required a medical appointment but her family physician was away, and thus she met with the covering physician. During her appointment Sarah disclosed her trauma

history and the covering physician responded negatively, making her feel that "the way you are treated is just garbage." Coincidentally, at a later date, Sarah saw this same physician in a different context, a walk-in clinic located near her workplace.

> The same doctor was there and didn't recognize me but I recognized her because I came in with my suit. I was working in financial markets, and the way I was treated for the same symptoms was night and day. Completely different, they took it very seriously...

Sarah's narrative highlighted the intersection of gender, trauma, and class. By attending a medical appointment clothed in business attire, Sarah embodied social capital and exuded the covert expectation that she should be taken seriously as a professional who would not waste the time of a fellow busy professional. Without the suit, however, Sarah could be dismissed as a hysterical, bored, middle-aged homemaker.

Figure 62: Scarbro's image of Pandora's Box represented:

> …when you start [working through the abuse] you can't stop, like you have to deal with everything… I didn't want to acknowledge the physical abuse because I was financially… depending on my parents. And the source of abuse is also the source of care… But in some ways I was fortunate that… I don't have to deal with the sexual abuse predators. They're not in my life. Or it was an episode and it ended. It wasn't continuous.

Systems of Gender, Class, Education, and Race

The embodied differences of gender and class intersected not only with trauma but also with education and race. Participants described that their level of education impacted their interactions with healthcare providers. This study, however, found gender differences in participants' identification of education as either a help or hindrance. For example, Scarbro

viewed post-secondary education as a protective factor and a "common ground" in his interactions with providers. Scarbro explained that education helped him to develop communication skills and resourcefulness, "which helps you seek this help."

In contrast, several female participants described that education was an obstacle in patient-provider interactions, especially when they were educated and employed in "pink collar" healthcare professions such as nursing. These participants reported that doctors dismissed their professional expertise and resented their questioning of clinical decisions. For example, Phoenix explained how she was not taken seriously by doctors because she was a black nurse with "medical knowledge" whose casual clothing conflicted with the image of the feminine professional and whose hairstyle embodied her race and cultural heritage.

> I had a very good income and I was the primary income person [in her family]. Then it lead to a bunch of disasters - part of it was because I had medical knowledge so that doctors didn't want to listen to the things that I had to say and I think part of it was my color. I've hit a lot of roadblocks because… I used to have dreadlocks, long dreadlocks, [and] I didn't fit the characteristic [of a nurse]. I'm an intelligent person but when you are coming [to appointments] in track pants… nobody really wants to hear anything that you have to say.

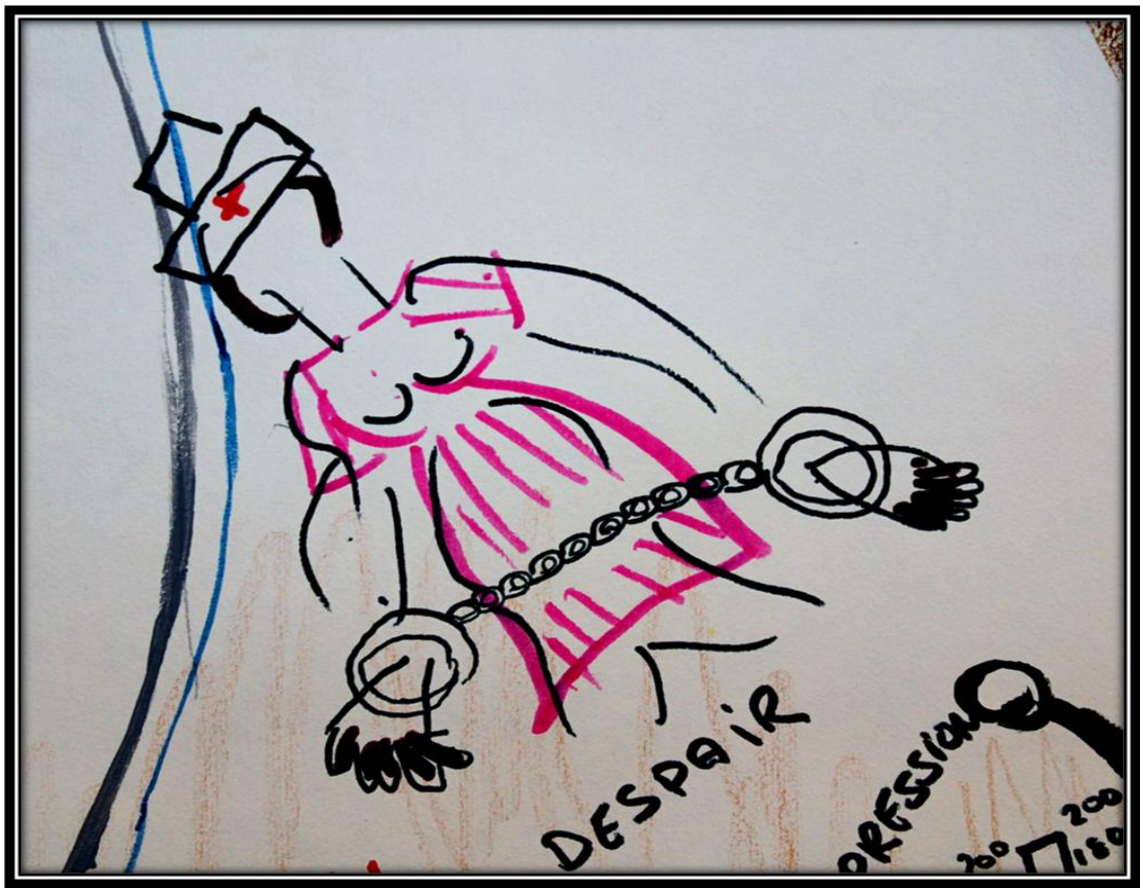


Figure 63: Phoenix explained the reasons why she was handcuffed in her profession.

> Being a woman, being a medical person… a nurse with extended skills - all that comes with a certain amount of knowledge. A lot of doctors found that intimidating and… even speaking as a patient going from being the medical person to being that patient that was a completely crazy flip….I try my best to not tell people that I'm in medicine. I always make a slip-up. They always find out, and it always changes the scenario so my career has sometimes worked really badly against me in my journey. Um, you can't take it out of me. There is no way to do that, so that part of me is always going to be handcuffed.

Similarly, as a black woman who previously worked as a nurse, Angelina encountered the intersection of racism and sexism in her interactions with providers. She also embodied cultural difference through her accent.

I didn't realize [the racism] at first because I was never the type of person to look at color and all of that and being a female as well. I'm not just cute [laughs]. I also have an education in the field and people don't correspond with you on that level if they don't know that you've got it. It can be used against you [her healthcare profession] I feel because you are able to get to the point quicker and they feel like you are trying to tell them what to do, kind of thing… I [have] an English accent, as well. So I don't know, people always said to me "oh I love the British accent…"

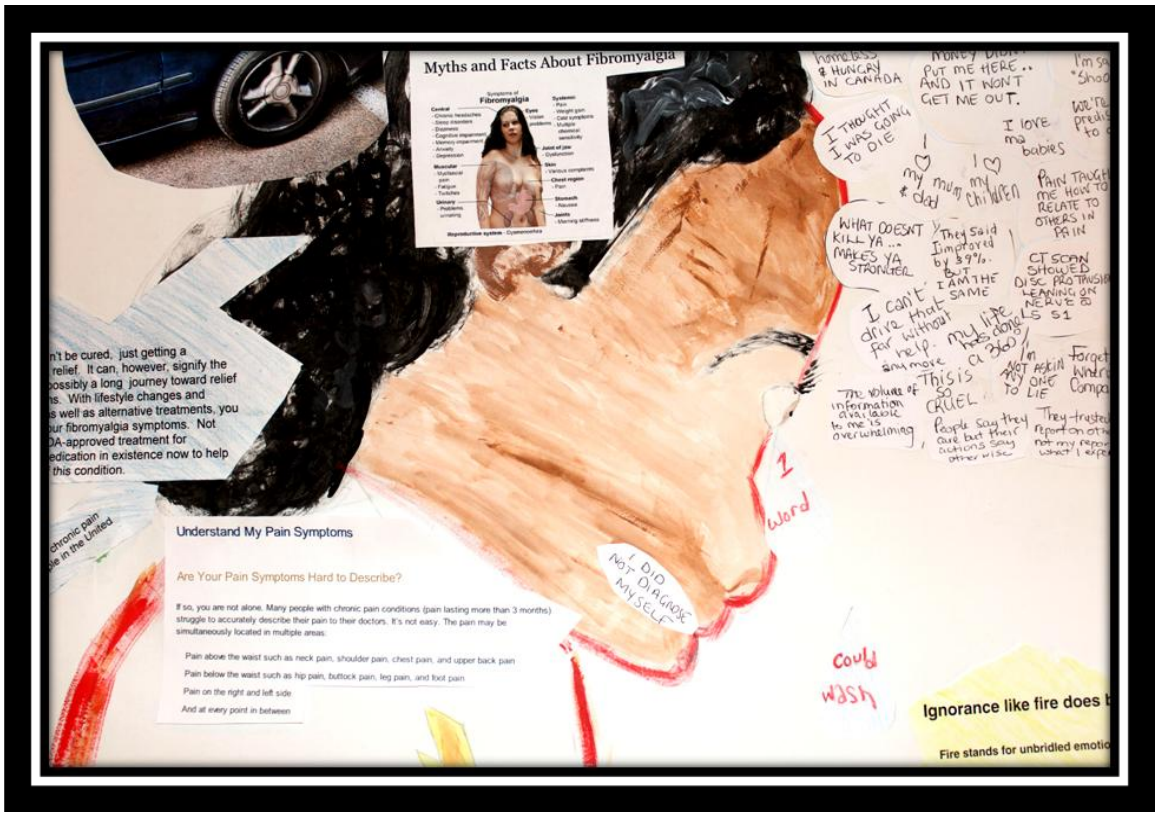


Figure 64: Angelina's representation of being a black woman.

In comparison to Phoenix and Angelina, most study participants ceased working because of their FM. These participants wished they could return to their previous work and level of functioning. This wish was shared by participants during a focus group session.

Saint Augustine: You know all of us kind of have – most of us I don't know about Marie, you are still in university and stuff, but most of us had a crashing halt to our career.

Sarah: Yes.

Marie: Well that is why I went back to university because *I was fired* from my job for being sick.

Saint Augustine: Every time I see something I love to do and I go and do it – you know, there is good and then ugh [makes exhausted sound]. The steam runs out and it doesn't take long.

Sarah: Yeah.

Saint Augustine: In some cases an hour or a week, or whatever it is the stream does run out and there is nothing there left to give. It's kind of frustrating because you stand thinking "man, I love this stuff", you know.

Sarah: I know I miss my career.

Saint Augustine: And I know that I want to do it –

Sarah: But you can't.

Saint Augustine: And I can't, I just can't.

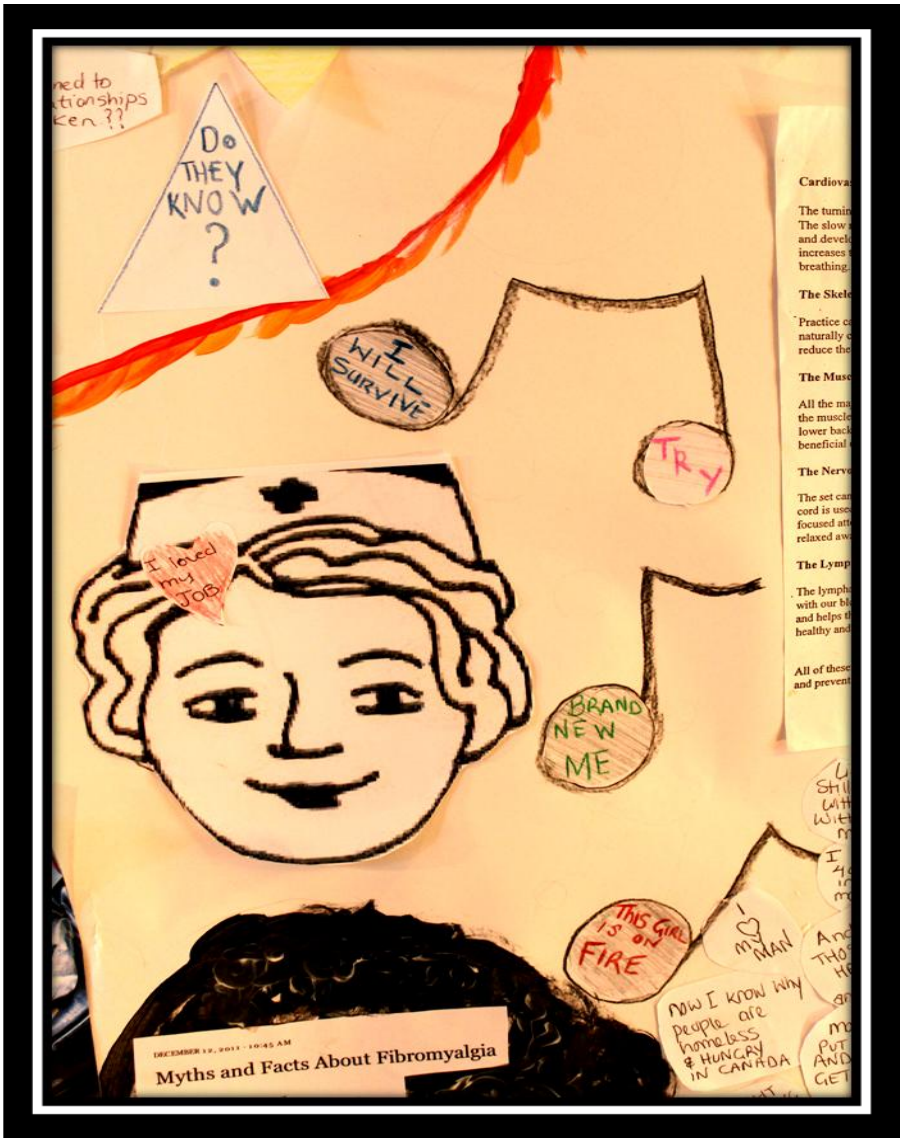


Figure 65: Angelina explained "there's a picture of a nurse. That was me. And I put this little heart on my head. I loved my job. Cause I did."

Many participants reported that unemployment contributed to their experiences of compromised care. Because of unemployment, many participants struggled financially. Darlene

described how these financial struggles were compounded by the process of trying to claim disability benefits.

> [Y]ou use up your RRSPs and then you have to use up your fifteen weeks of UI [Unemployment Insurance] and then you have to go on OW [Ontario Works – social assistance]. Now this, of course, is for someone who is single. I don't know what it's like with a partner. The money that they give you, you can't live off of. Who the hell can get an apartment for four hundred and forty-four dollars? You can't even rent a room… We go through all that just so they can give us money and… it isn't that much.

As a result of these financial barriers, some participants reported that they could not afford the cost of travelling to medical appointments while others were forced to discontinue medical treatments that were not covered by OHIP. Consequently, participants' systems of unemployment-class-financial differences impeded their access to healthcare services, which were potentially beneficial.

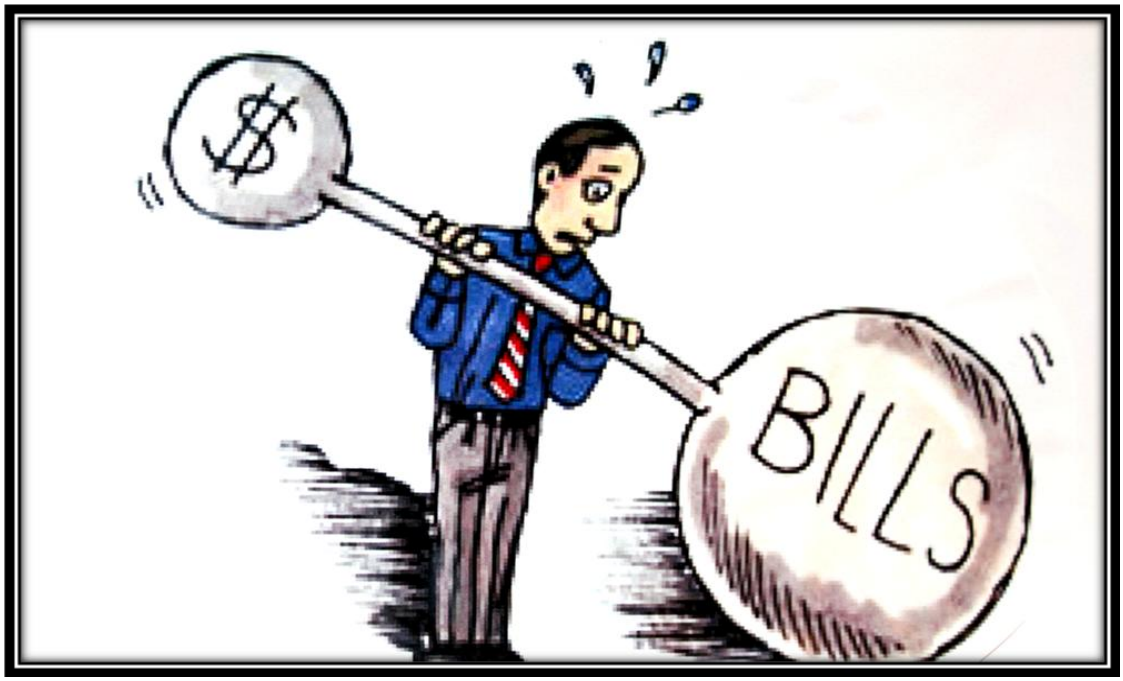


Figure 66: Scarbro stated that treatment "costs a lot of money and pain." He stated "the financial stresses around not being able to work. And all the debt that accumulates around it. There's a lot of shame and guilt around that."

Systems of Gender, Class, Race, Culture, and Geography

In addition to class, participants reported that the intersection of gender, race, and culture impacted their healthcare experiences. For example, Scarbro immigrated to Canada over a decade ago and belonged to a middle-class family. He hypothesized that he received more help from providers compared to recent immigrants who were lower income and less acculturated. In comparison, several female participants described the obstacles of being recent immigrants navigating an unfamiliar healthcare system. For example, Rare Gem explained that she had an appointment with a hospital doctor whom she had not previously met. At the hospital, Rare Gem asked people for directions to the doctor's office but found "people don't even *talk* to you."

Some participants identified differences between the healthcare systems in Canada and their countries of origin. For example, Rare Gem explained that while living in India she had "never heard" about the diagnosis of FM. As a result, she questioned whether FM was "more common in [the] West" than in East India and stated "I feel like that [FM] is not prevalent in India." In addition to cultural differences in diagnostic constructs and medical terminology, Rare Gem compared the treatment of female patients in Canada and India. Rare Gem interacted with a Canadian doctor who "did not respect women", but observed sexism "here in this country it is not so *bad* as compared to India." Despite the possibility of encountering sexism in India, Rare Gem contemplated returning to India for treatment because she felt that her country of origin possessed a more integrated model of care than the Canadian system.

In addition to identifying differences between Canada and other countries, participants discussed the inequitable distribution of healthcare resources both within and across regions of Ontario. For example, many participants found that FM services were primarily located in downtown Toronto. Interestingly, the participant, Scarbro, selected his pseudonym to represent this geographical disparity; he was a man, a "bro," living in an underserviced suburb of Toronto. As a consequence of geographical barriers, participants -- who lived outside of Toronto in other cities towns, and rural areas -- travelled lengthy distances by car or public transportation to access health care services. These participants reported difficulty in traveling to Toronto because of illness, financial constraints, and/or poor weather conditions. Interestingly, participants discussed geographical differences in both the access to and quality of services. For example, Rare Gem described that she lived in an "immigrant area" of Toronto and could "feel the difference" in the quality of care provided in her local hospital compared to downtown hospitals. She stated, "There's so much discrimination. Like why can't we have the same facilities here, the

same good doctors here?" In downtown hospitals, she reported experiencing the convenience that all the tests were "immediately done and everything was done there [on site]… And same day I saw the doctor… and then immediately she gave me appointment. And the neatness, the clean… Here, I don't *find* any good doctors…" Rare Gem repeatedly used the term "here" to refer to the lack of "good doctors" and efficient services in the neighborhood in which she lived.

While some participants compared the quality of care within Toronto hospitals, others compared the quality of care across provinces. For example, every few months, Marie travelled to a different province to attend appointments with supportive medical specialists. These specialists "have been super big supporters or big believers in fibro and they never made me feel like, you know, I'm crazy or that my symptoms aren't real. They have a legitimate interest in wanting to make sure that I feel better." In comparison to Marie's narrative, several participants reported a similar experience of having a supportive physician who left Ontario. These participants explained that they could not find new doctors who provided a similar level of support as their former doctor.

Chapter Summary

In this chapter, I have reported that many participants discussed their healthcare experiences as not merely gendered experiences. Instead, they described a myriad of ways in which they embodied an interconnected system of differences, and they reflected upon how these differences shaped their healthcare experiences.

Figure 67: Rare Gem experienced compromised healthcare due to geographical barriers.

CHAPTER SEVEN – FINDINGS

STRATEGIES OF RESISTANCE

Figure 68: Marie's body map: "I just wanted to show myself as being strong."

In the previous two chapters, I reported the findings about participants' experiences of compromised healthcare. In chapter five, I reviewed how participants' encountered compromised care due to structural barriers and negative interactions with healthcare providers. In chapter six, I described another dimension of compromised care; I reported the ways in which participants' embodied differences impacted both their interactions with providers and ability to access resources. These respective chapters convey many participants' narratives of systemic obstacles and overwhelming suffering. Within these narratives, participants also shared their inner-strength, bravery, resilience, and strategies for resisting the system of compromised care. For instance, these qualities of resistance and resilience are defining themes within Marie's body map. I open this chapter with Marie's map because she portrays herself as a super hero through her body position, use of primary colors, and pictures of super heroes representing her own heroic support system.

The majority of participants including Marie illuminated the overarching theme that they resisted the system of compromised healthcare by developing and implementing strategies of self-management. In this chapter, I report the findings about participants' self-management strategies, including self-advocacy, educating providers and the public, seeking alternative healthcare treatments, practicing self-care, experiencing and embodying self-efficacy, as well as finding peace and strength through spirituality.

Self-Management

Self-Advocacy: Participants Asserted their Right to Receive Unbiased Care

Although the majority of participants fought to receive adequate healthcare, this fight involved extensive time and energy. As Sarah stated, "I have this image in my head

of medical need and instead of having the medical needs addressed all the energy is going to fighting prejudice and victimization. It's victimization." In order to resist victimization, many participants, who belonged to different genders, ages, cultures and races, described the necessity of advocacy for themselves. Participants explained how self-advocacy required the confidence to communicate in an assertive manner with healthcare providers. For example, Stu explained he visited a neurologist who performed "every neurological test on me that he could." Afterwards, Stu "had a real problem" with this doctor because "he called me in the last time and said, 'well you have a million dollars worth of tests and you are perfectly fine. You don't have a problem, see ya'." In response, Stu expressed his anger towards the doctor.

> [W]hat are you fucking talking about? How can you be so stupid? You are supposed to be a really top guy, and you can't figure out this straight forward thing? These symptoms are blatant and obvious. Just because you don't know the answer. And I said it in front of his student too. You aren't smart enough to figure it out, don't blame me.

In comparison, Marie stated, "I think I am giving a bad impression of myself in a way. I am outspoken so if somebody shows me disrespect I tend to give it right back to them, as like a warning." Marie not only verbally stood up for herself, but also physically stood up and left a medical appointment she felt was discriminatory.

> [T]he rheumatologist… saw the diagnosis of fibromyalgia [as] his rationale for not wanting to see me anymore even though I have an autoimmune disease, lupus. His rationale was fibromyalgia is a syndrome, so it's not real. "I don't deal with fake things – I deal with real diseases so if you want to come and see me and talk

about your lupus then I am prepared to listen to you but if you mention any of your fibro stuff there is the door." I turned around to him and said "well I'm the patient, you are the doctor. You are the one that has the expertise. I don't know what are lupus symptoms and what are fibro symptoms so when I come to see you I'm going to tell you everything, you can figure out what goes in which category and then you can talk to me about the ones you feel fit in your narrow little spectrum" and he just looked at me and he said "well, there is the door" and I said "yes, there it is" and I got up and left.

Stu and Marie's examples highlighted that self-advocacy involved not only direct communication, but also asserting the right to end interactions when said communication did not change providers' negative attitudes. In comparison, other participants reported that ongoing self-advocacy could eventually lead to improvements in providers' attitudes towards patients with FM. For example, Phoenix described how she resisted her family doctor's practice of prescribing medications while attempting to develop rapport.

I tried a collage of different medications, my new doctor was very frustrated with me and I was equally frustrated with him. We didn't like each other, but he was stuck with me and I was stuck with him so I had to decide how was I going to figure out the relationship with him… and I bought him a book on fibromyalgia and I put it on his desk and said "you read it and I'll come back and we'll talk about it." He wasn't too impressed with me at the time, but now we have a much better relationship and he's listening to me, and it's working… he accepts me now and we sit down and do things together. So I think eventually I'll end up with a good relationship like that, but not right now.

Phoenix' narrative highlighted that self-advocacy required perseverance, as well as a lengthy process of education.

Education: Participants Taught Providers, Themselves, and the Public about FM

While some participants used education as a collaborative tool to guide their healthcare treatment, others used education to resist their diagnostic limbo. After years of encountering perplexed and dismissive doctors, for example, Weezie found a medical explanation for her undiagnosed symptoms.

> I kept going to the doctor with all these weird symptoms *for years*. Nothing showed up on any of my tests… Then I read an article in the *Toronto Star*. I saw my life and symptoms in print for the very first time. I knew it was what I had but I hid the newspaper article in a drawer. It scared me. At the end of the day I retrieved the paper and threw it out. I'm not buying into this, I'm not sick. Eventually I had to give in and go see a rheumatologist. She pressed on a trigger point that I didn't even realize I had and I jumped off the table. I had fibromyalgia.

Many participants took ownership for educating both providers and themselves about FM. Participants learned about living and coping with FM by reading self-help books, researching websites, and attending support groups. For example, by participating in a support group, Hope broadened her knowledge about integrating FM treatments from both allopathic medicine and CAM.

> [I] learned a lot of things that can help me cope with what my current condition is instead of fighting it… so now with that I am now pursuing, going towards physiotherapy, acupuncture, holistic naturopath and the homeopathic side of the

medical field, which the government has not really recognized but apparently the effectiveness is better than pushing pills...

Participants' exposure to education about FM varied both within and across focus groups. Several participants reported that prior to attending the focus group sessions they had never interacted in a group with people with FM. In comparison, some participants disclosed that they were either previous or current support group members while other participants reported volunteering in support groups and community organizations. Angelika, for example, described that as a support group leader she provided outreach and education, which in turn led to a personal sense of empowerment.

> … I personally have been an advocate for fibro… I am talking from experience. I've been at this for twenty years or more, I've seen people, they have come to the [support] group, they come, they – initiated what I have indicated… And that's an accomplishment to me… I've helped one more person then I've done something and I feel fulfilled. That's what keeps me going forward.

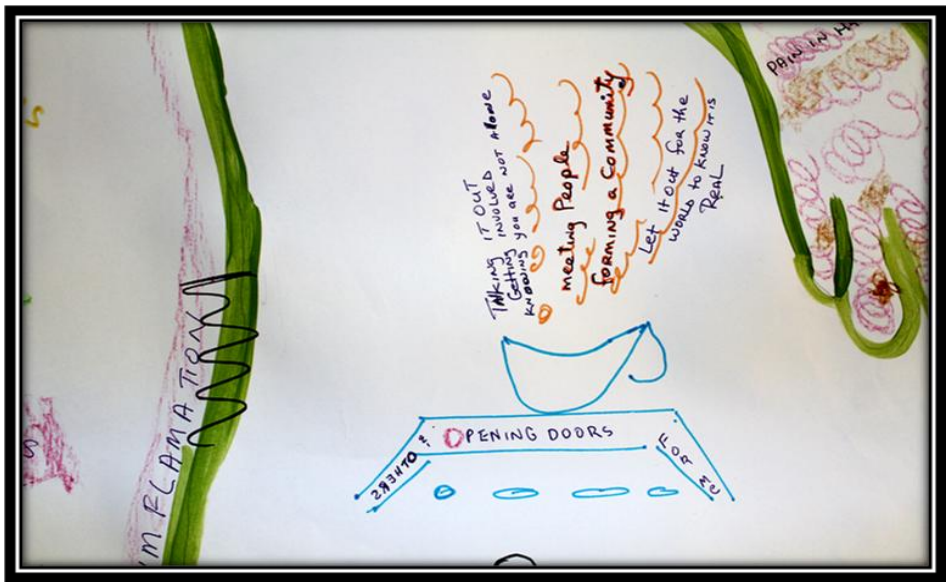


Figure 69: Angelika drew a coffee cup to depict “opening doors” for people with FM. She listed the benefits of connection: “talking it out; getting involved; knowing you are not alone; meeting people; forming a community; let it out for the world to know it is real.”

Figure 70: Geraldine explained that while engaging in a support group “all of a sudden not only was I helping myself but helping other people and that was always important to me. So there was like a give and take… the point of the group was to always look forward...

Figure 71: Susan volunteered at the Canadian Pain Coalition and created Pennies for Pain.

> I was the instigator [laughter]. It was my idea to create Pennies for Pain so, I'm glad that the Pain Coalition took up on it and went with it. The idea behind it is many people live with chronic pain but if the 6.8 million Canadians each gave us a penny we'd have 680, 000 dollars every year.

Participants sought education and empowerment in the milieu of support groups, as well as in focus group sessions. In these sessions, many participants described experiencing social isolation and found that the reciprocal process of sharing information with and learning from other participants led to a sense of relief and belonging. Despite the empowering benefits of education, I attempted to maintain the purpose of the focus groups by encouraging participants to continue sharing information after the sessions. In one session, however, a participant challenged my request, explaining that these

information sharing conversations were necessary because there was a dearth of reliable information about FM in comparison to publicly recognized diseases such as cancer.

During the focus group sessions, participants both verbally and visually shared information about FM. Some participants filled their body maps with facts and statistics about FM to educate the public, thereby decreasing stigma and increasing awareness about the condition. For example, Lori listed all the symptoms of FM to educate the medical community that FM was more than a chronic pain condition.

> I also put from the [name removed] website a list of the majority of what our symptoms are and it is not just pain. So I thought if this [the research study] goes as well as you would like it to go and it [the findings] goes before the medical community, they have to stop talking about it as being just a pain disorder because it is way more than that. We deserve more.

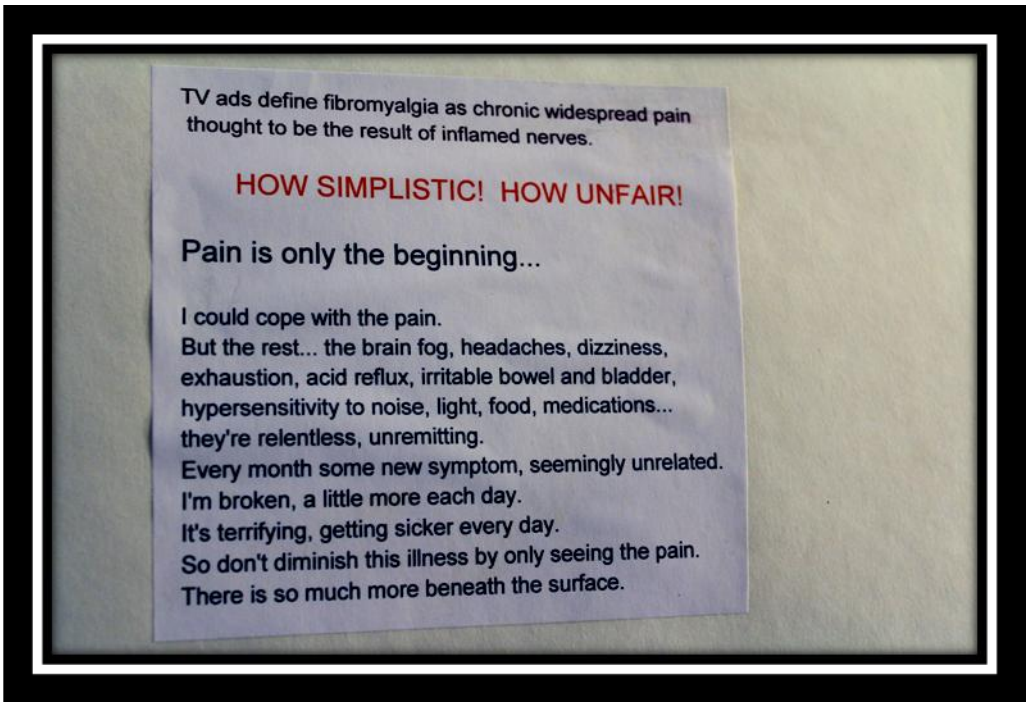


Figure 72: Lori argued that the media incorrectly defined FM as solely a pain condition.

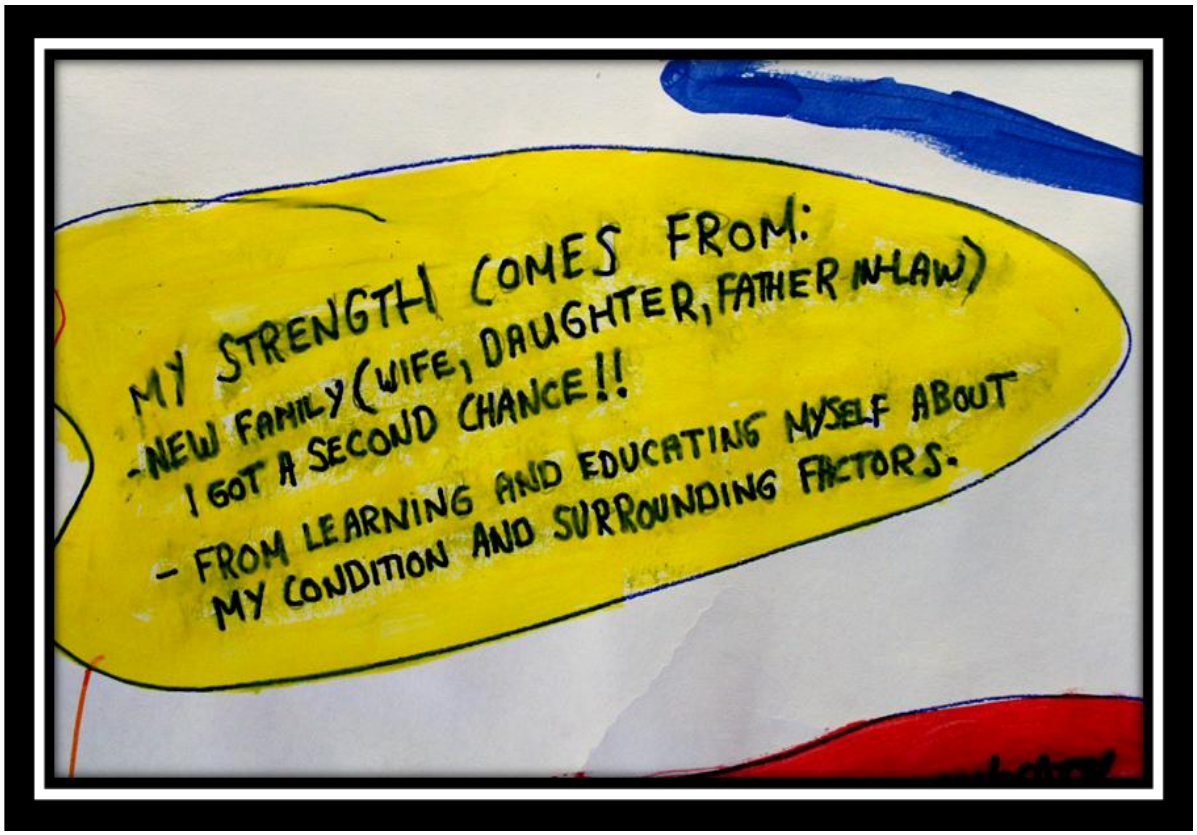


Figure 73: Brian's strength came from "learning and educating myself about my condition and surrounding factors."

Figure 74: Angelina covered her body map with FM information to educate the public.

Seeking Alternative Healthcare Treatments

Through education and firsthand experience, the majority of participants learned to seek treatment for FM outside of the allopathic healthcare system. Many participants found that allopathic providers were limited in their knowledge of FM treatments and overprescribed medications, which were neither symptom-alleviating nor tolerable due to side effects. As a reaction, participants explored CAM treatments provided by naturopaths, osteopaths, massage therapists, chiropractors and nutritionists. For example, Hope reported that her doctors prescribed a plethora of medications such as antidepressants and opiates, which targeted different neural pathways for pain reduction.

> I was bombarded with a lot of different medications and antidepressants … they never really worked for me. They gave me worse side effects than my current condition… I took a lot of painkillers. Naproxen was a favorite [laughs]. But I'm not supposed to take a lot of that, nobody can depend on that.

Over time, Hope learned how to integrate supports from her family physician and alternative practitioners. In comparison, Phoenix explained she "stumbled into medicine which was natural medicine… dealing with a naturopath, I started going to physiotherapy. All these things I found by myself because the doctor that I had, the new one, was useless to me at that time."

Figures 75: Hope explained, “through the [healthcare] journey I drew one of the doctors who told me to look for a support group and I put a lot of flowers there because that’s been very fruitful.” Hope drew branches to connect her CAM resources to signify “whether we like it or not everything is interconnected.”

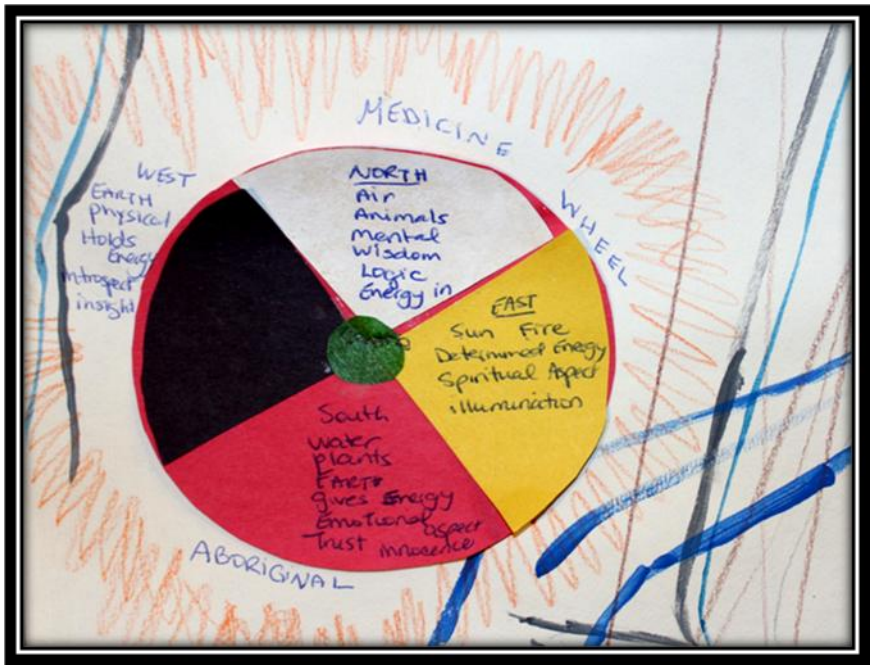


Figure 76: Phoenix explained that "the medicine wheel is a very big part of my life…"

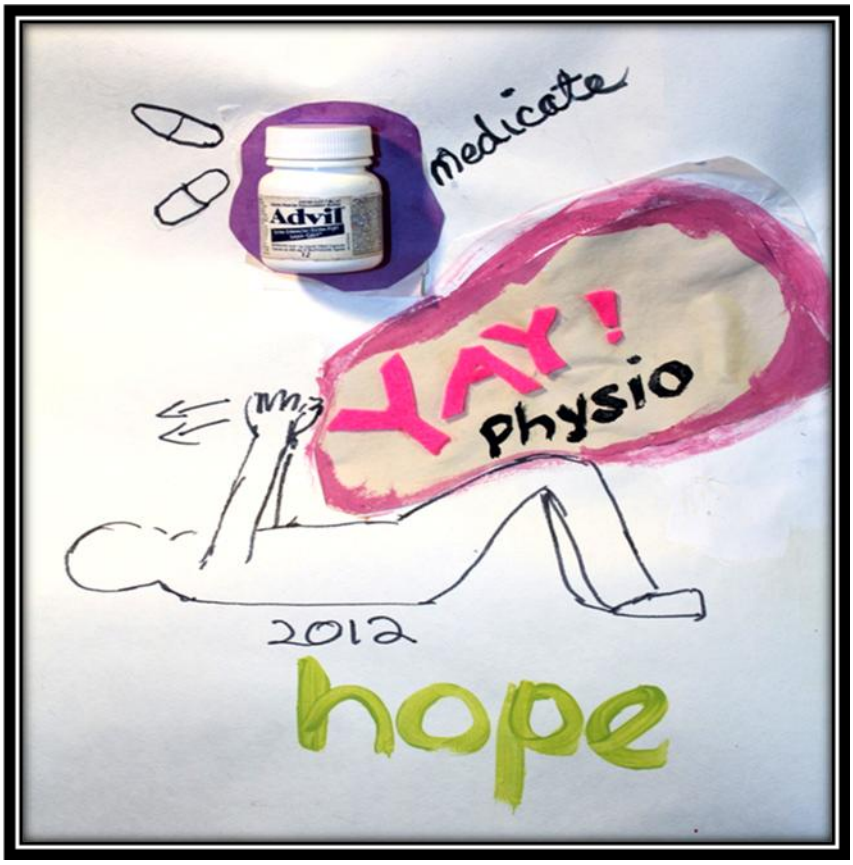


Figure 77: Fran integrated different methods of pain relief such as medication and physiotherapy. She stated, “This is my physiotherapist, I consider her my savior” and “this is me doing exercises.”

Figure 78: Peanuts’ surrounded her body with the healing hands of providers such as her chiropractor. She drew her chiropractor in a heart, signifying, “I’ve been going to a chiropractor now for almost ten years. I go twice a week and she’s helped me a lot…”

While some participants embraced CAM treatments, others reported initial feelings of skepticism. For example, Brian decided to pursue alternative treatments, but he did not fully believe in these treatments until he experienced increased bodily awareness and reduced pain.

> …I was in constant pain, and then it would get so profuse. I kept thinking, rather than just give up and lay on the couch and accept all these medications that were causing me to gain weight, I thought I want to go for each area of pain and start to get therapy for those pains and okay I've been told I have fibromyalgia but I've got these really sore areas but I can't isolate them and then I took this meditation mindfulness chronic pain with [doctor's name] and she taught me know to meditate. I thought that was all just a bunch of baloney, but she taught us and I started to learn and realized the mindfulness segment, she did something called a body scan and then I started to find out that there were three or four areas in my body that were really hurting and I started to separate it. Once my physiotherapist pushed there and it went away and I thought this is great!

Some participants found that CAM treatments were more effective than allopathic treatments, eventually abandoning the mainstream healthcare system. For example, Anna explained, "the medical community didn't have a lot for me so I did go down that naturopathic route. It's very expensive but I did feel like there was more of relief from the naturopathic side verse the medical side..."

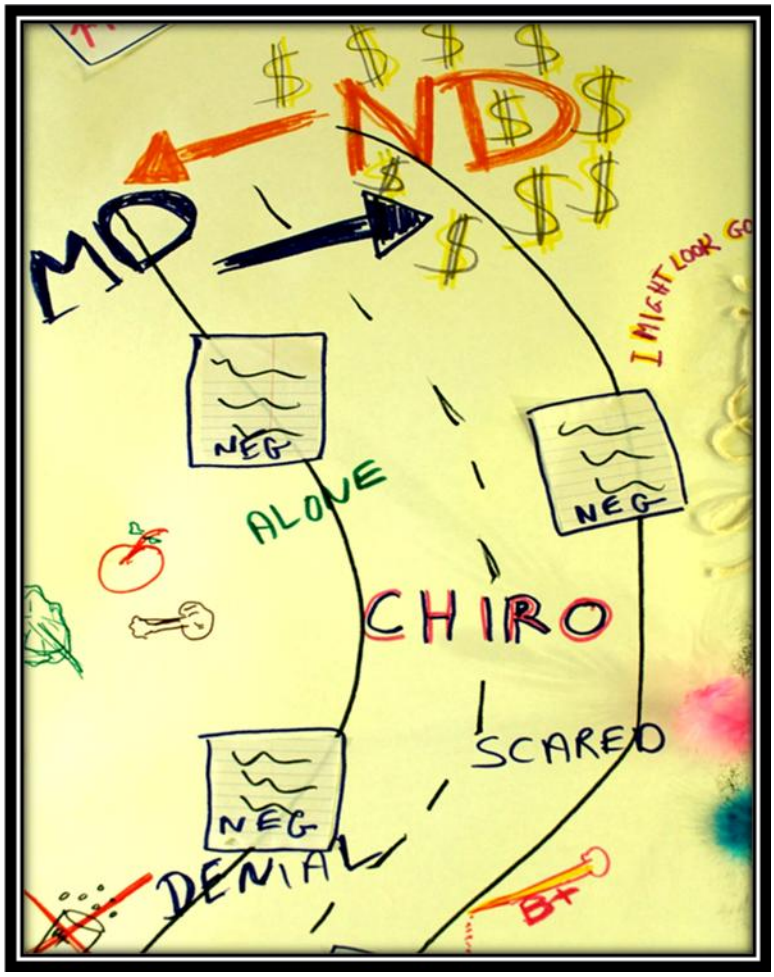


Figure 79: Anna represented how her healthcare journey involved deciding whether to travel down the road of medicine or expensive naturopathy.

Anna's quote raised a key theme echoed by many participants: despite their efficacy, CAM treatments are costly and are not fully covered by OHIP or insurance plans. Because of the prohibitive costs of CAM treatments, some participants made financial tradeoffs by reducing their intake of expensive supplements and frequency of treatments. For example, several participants reported that receiving weekly massage therapy sessions helped decrease their muscle pain while reducing the frequency of these

sessions led to increased pain. These participants required consistent massage therapy sessions in order for their bodies to tolerate and eventually adjust to the physical pressure of the intervention. As a consequence, several participants who could not afford weekly massages were forced to discontinue the treatment.

Despite financial barriers, many participants who could afford alternative practices found them immensely helpful. For example, Weezie experienced relief working with a naturopath who provided a multi-faceted treatment approach.

> I received B12 injections, behavioral talk-therapy, deep tissue massage, hot and cold showers to boost adrenal glands, advice on diet, vitamin supplementation, and cod liver oil patches, acidity testing strips, tapping, food sensitivity testing, stretching and breathing techniques, acupuncture and last but not least exercise.

Practices of Self-Care

Many participants resisted the limitations of the allopathic healthcare system by not only seeking CAM treatments but also adopting practices of self-care. Participants' reported that their self-care practices involved a combination of gentle exercise, healthy nutrition, meditation, and sleep hygiene. For example, Evelyn explained, "I need to alleviate stress and meditate and breathe and I mean deep breathing, exercise, find gratitude and release through writing journals again." Some participants emphasized the centrality of self-care for maintaining a sense of wellbeing. For example, on her body map, Peanuts wrote "'my message is to take care of number one first - and that is me!' I think for all of us that is more, the most important thing."

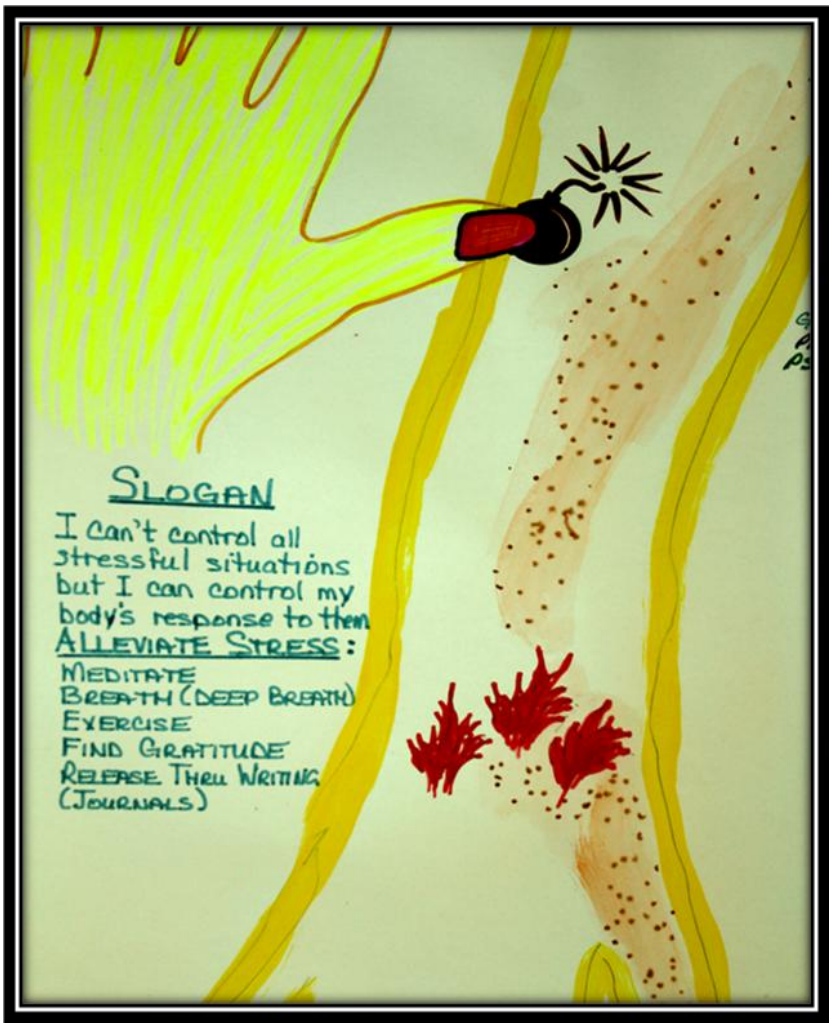


Figure 80: Evelyn listed her self-care practices and explained her body map slogan was: "I can't control all stressful situations but I can control my body's response to them."

Many participants described that self-care practices were necessary yet time-consuming. These participants assumed responsibility for finding, implementing, and continuing to practice routines of self-care routines. In one focus group session, for example, participants discussed the ways in which self-care was a fulltime job.

Angelika: …it's a job. Your fibro is a job because every morning you get up and you got to think about how you are going to feel a little bit better so that you can support yourself.

Saint Augustine: So that you feel ready to do something, you know.

Angelika: …you have to keep motivated and keep on moving because you can't stay stagnant, you can't, you have to keep trying to stay healthy.

Participants reported that self-care was a full time job partly because it involved learning about their bodies' capacities for endurance, energy levels, and pain thresholds. Many participants learned to modify expectations about their bodies for self-care strategies to be effective. For example, Fanny Freckles described that after she began aqua-fit exercise, she spent days recovering from the resulting fatigue and pain. She eventually discovered a gentle form of stretch-based aqua-fit, developed a passion for daily practice, and became an aqua-fit instructor for people living with chronic pain. She stated, "It [aqua-fit] really helps because it gave me a focus outside my pain and I think once we find that it really helps to diminish the monster you know." She explained that a key to success involved learning techniques for pacing her energy.

You have to pace yourself you know. That is my four letter word and so when I'm working in the garden the timer will go off and then I'll count down. I'll just do one or two more things and then it's clean up time, right. That pacing is really important. I will survive - nobody has died of fibromyalgia yet. We just have to find a way of coping with it.

Sometimes coping strategies involved extreme measures such as breaking the law. For example, Darlene experienced severe pain, and her suffering was evident in the focus

group sessions. She disclosed smoking marijuana for temporary pain relief and planned to obtain a physician referral to a medical marijuana clinic.

> Oh I don't get that yet, [medical marijuana]. I'm still waiting for that. I'm still doing it illegally [laughs]… I tell everybody all my doctors and everybody. Even a cop lives upstairs and my daughter was saying you are going to have to quit smoking. I'm like no. I just sit in my back room.

Figure 81: Darlene's narrative shed light on the fact that participants had to be proactive and at times rebellious in order to manage debilitating symptoms.

Figure 82: Fanny Freckles drew "a recurring theme of the waves going through [the map] because the water is the only thing that seems to soothe my fibromyalgia and so it makes me feel good." In the middle of her swimsuit, she displayed her future dream of starting a "warm water place, it's a centre for fibromyalgia and chronic pain wellness." At the bottom, she represented that she "used to be a strong swimmer and the fibro prevents me from doing that."

Figure 83: Weezie drew herself from a side profile.

> My body is in the jogging position as this represents me at my optimal best, exercising helps chase away the blues… It is how I manage my symptoms most effectively... The eyes are very large on the face as they represent looking to the future for opportunities and education, a cure.

Self-Efficacy

Through practicing self-care, participants experienced a sense of efficacy. Many participants described self-efficacy as a form of empowerment, which involved feeling in control of and gaining mastery over their FM. For example, Geraldine explained, "I can do it… be it physical or emotional or spiritual, I've got a hand on it. I'm the one taking care of it. I don't know how I can do it, but I'm going to do it." Geraldine's self-efficacy came from a spirit of determination, hope and positivity. Geraldine displayed her positivity by placing a collage of future-oriented images above her head in her body map.

> Above and beyond my journey of pain and all that stuff. I want [my life] to go this way. I want to travel. I want to be with people. I want to open new doors… I just want to go. I want to spread my wings and reach the sky and that may be different from what my brain says what my body can do, but I still want it…

Like Geraldine, many participants both verbally and visually expressed the importance of determination, as well as of being open to possibility, feeling grounded, envisioning a hopeful future, making choices, enjoying activities, and maintaining a sense of humor.

Figure 84: Geraldine stated: “One of my favorite sayings is when you get lemons in your life make lemonade.”

Figure 85: Phoenix drew a tree in her head because “it is my tree of life… I’m still grounded. I’m still doing all the good things I need to do to take care of myself. The tree is strong, I am strong.”

Figure 86: Susan explained, “Then this is my bubble gum for blowing bubbles to show that we – we still have to have fun in our lives.”

Despite embracing hope and positivity, many participants battled both internal and external forces in order to develop and maintain self-efficacy. For example, Moira explained, “you struggle with yourself, it’s a battle of your own will, as well, and you

want to be normal but you know that you are not anymore so it's a tug of war not just with healthcare but yourself…" In comparison, Evelyn recounted that in her healthcare journey, she battled not only "some very abusive doctors" and insurance companies, but also her own inner-conflicts. Evelyn developed self-efficacy by learning coping skills.

> I didn't ask for this and none of us does. The mind-behavior body...you know it is a therapy to gain some sense of control and develop coping skills. Mind and the body really are not separate skills [and] entities; they are supposed to work together and so, I believe to a large degree that... if we control our mind to be positive and to do whatever needs to be done – I'm not saying that we don't have setbacks but that's the way to go because they other way sure wasn't helping.

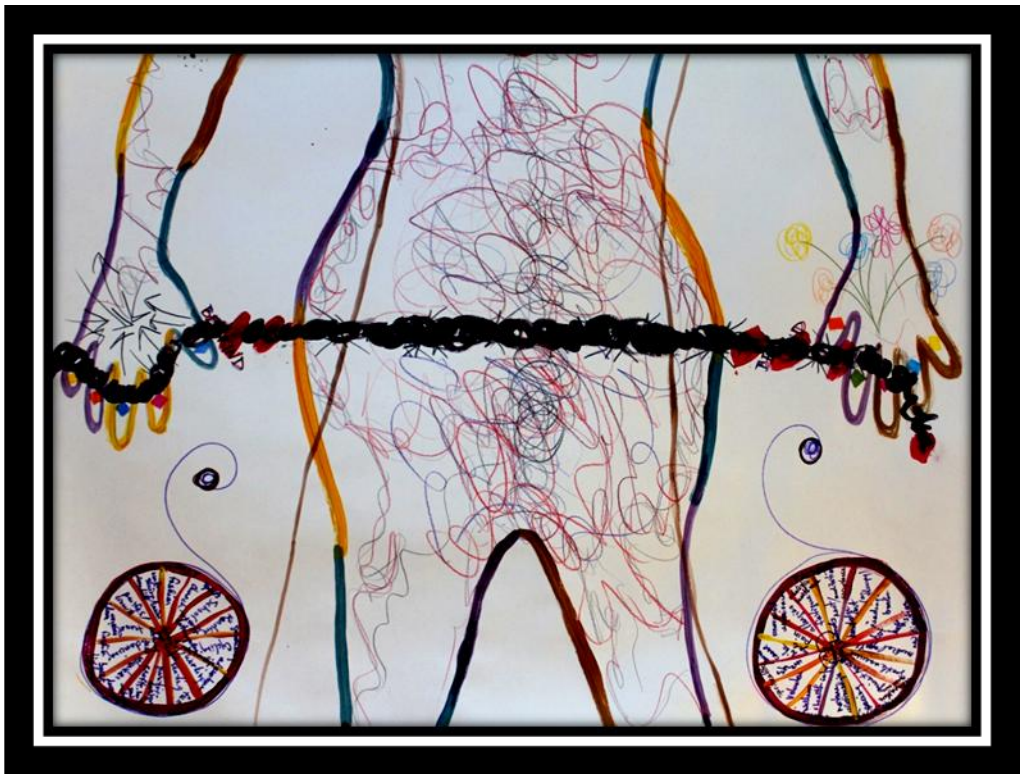


Figure 87: On the rope, Moira wrote "tug of war" to depict her inner and outer battles.

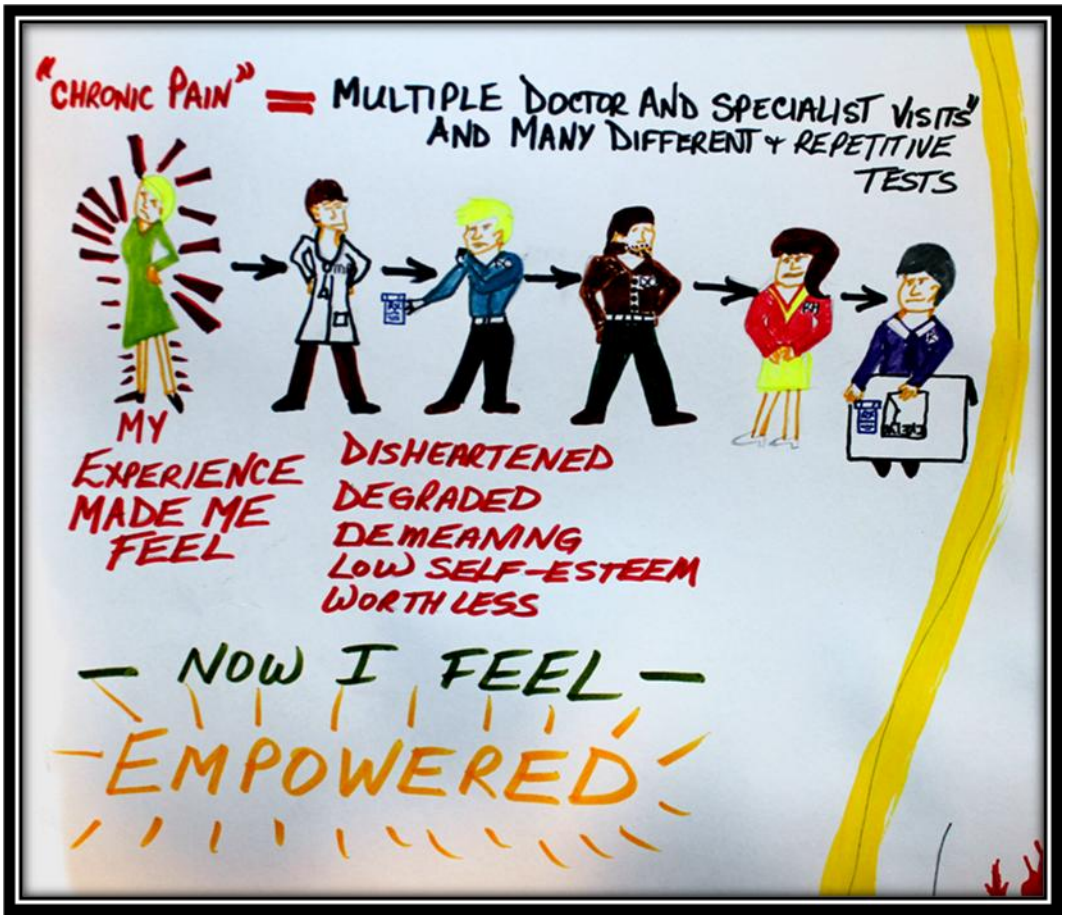


Figure 88: Evelyn explained: "Chronic pain was my experience [that] made me feel disheartened, degraded, demeaning, low self-esteem, worthless… I found some *very* abusive doctors out there, physically and emotionally. They shouldn't be practicing. Now I feel basically empowered from fibromyalgia."

Embodiments of self-efficacy.

Many participants' verbally and visually described how self-efficacy was not only a state of mind but also an embodied experience. Although participants represented their embodied states of self-efficacy in different ways, they conveyed a common message of resistance: they would not be overtaken by negative healthcare experiences. For example,

several participants such as Geraldine created body maps focused on the positive aspects of their lives in order to reflect they had moved beyond negative healthcare experiences.

Figure 89: Geraldine created a collage of images in order to inspire hope.

In comparison, some participants such as Evelyn and Angelika depicted their positive and negative experiences on different sides of their body maps, thereby conveying a balanced perspective, both literally and metaphorically. Furthermore, Weezie uniquely depicted this division. She covered her body map with an overlay of tissue paper -- displaying her FM symptoms and negative experiences -- which can either be rolled up or down. Weezie selected tissue paper because its transparency enables the audience to view her underlying body map filled with positivity and hope.

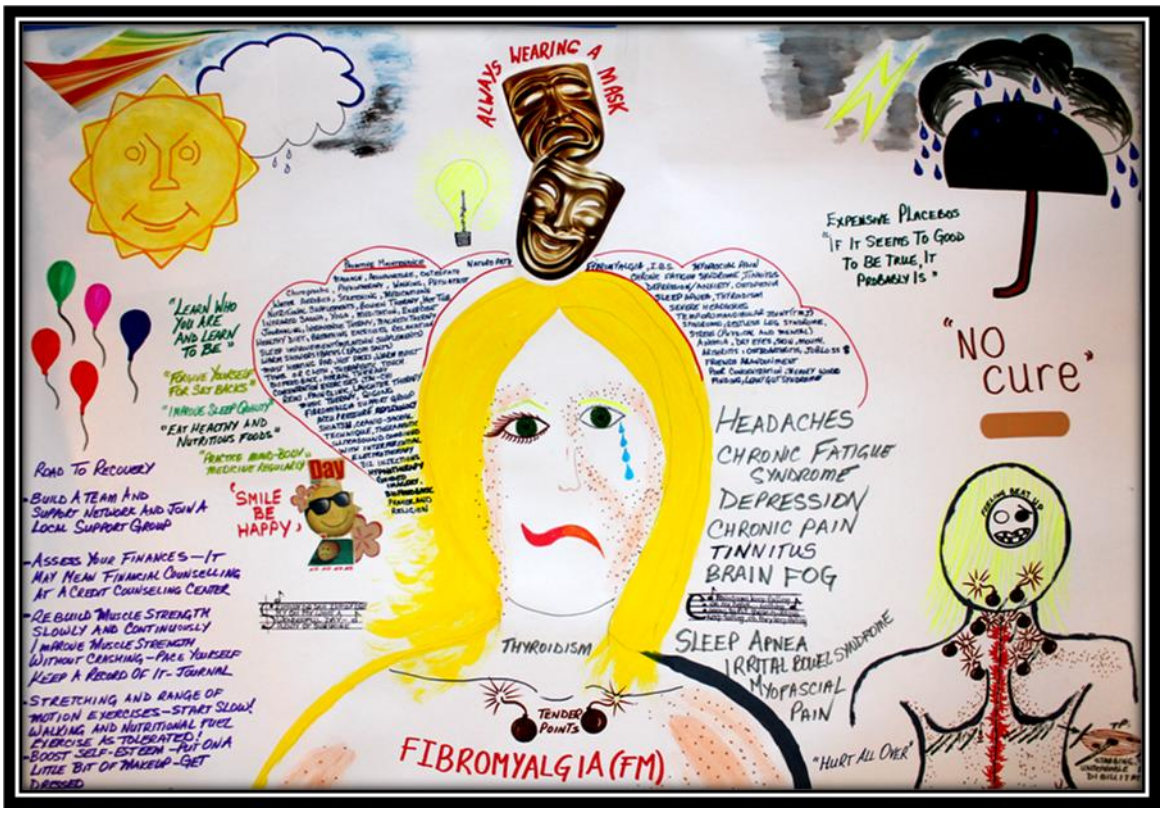


Figure 90: Evelyn explained the symbolism of the right and left sides of her map.

> …the left side it is more of the positive as prior to fibromyalgia but it's also my positive outlook that I try to follow everyday now in my life. The right… shows my journey from having fibromyalgia... even though I am more positive on this side there are still things that I had to deal with and at the top I've got the sun, the

clouds, there is still a little bit of darkness. There is still a bit of tears, but I try to look for the rainbow in life. Balloons always make you feel happy…

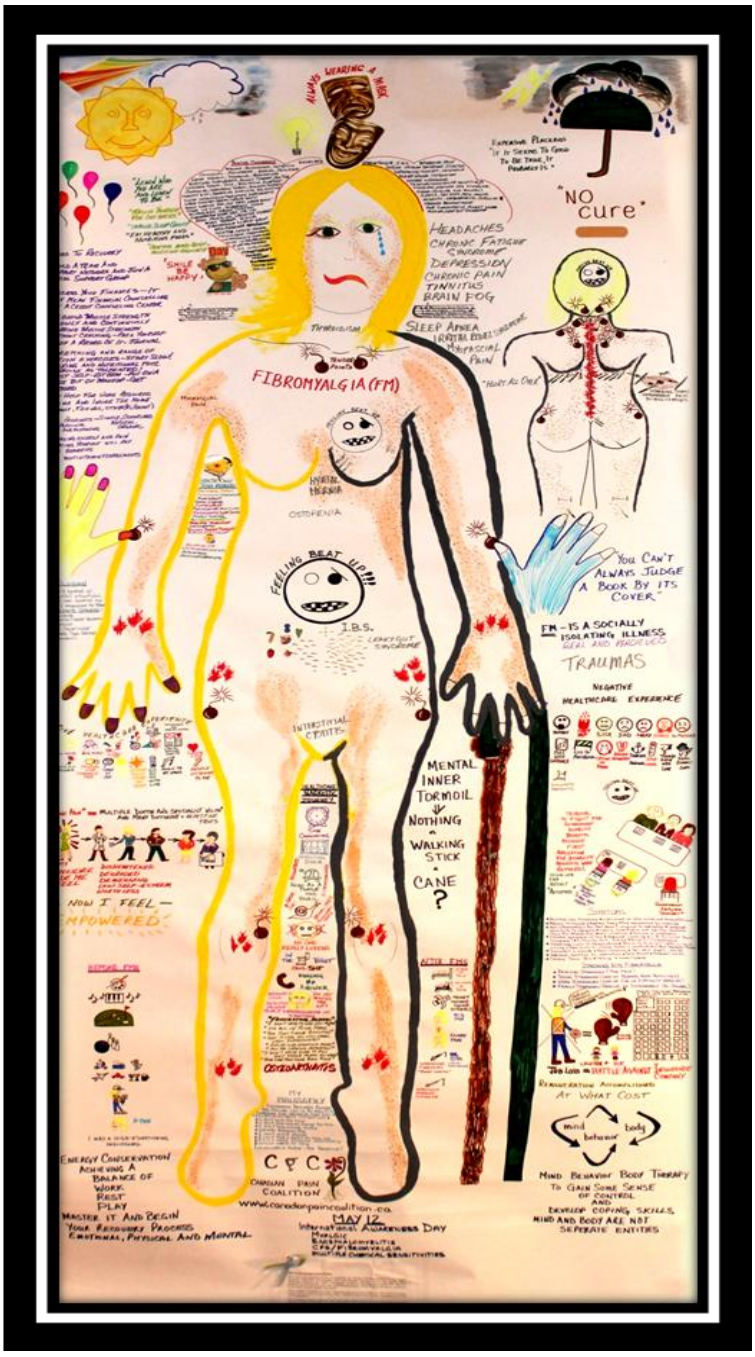


Figure 91: Evelyn's body map.

Figure 92: Angelika's body map.

> I was in the darkness when first diagnosed but slowly with different approaches I emerged into the light and got a handle on how to stay healthy without doctor's care. I took an approach to move into a positive state and frame of mind… I am better and stronger person from what I've been through.

Figures 93-94: Weezie's body map.

The purple grey veil that comes down is me experiencing a fibromyalgia flare up. All the words written over the top are the symptoms I deal with when the fibro fog hits. The reason I did it is this way, so when the fog lifts my happy life story is always there beneath, always trying to be whole and healthy again, my optimism.

Similarly, several participants, including Hope, Marie and Stu, drew two subject positions on their body maps: their ill self and healthy self. Interestingly, these participants drew the ill self as both smaller and spatially lower than the healthy self, representing the desire to overcome adversity.

Figure 95: Hope explained that before FM, "I was healthy and it was good. This is what happened [illness progression] and eventually with the help of everybody else, I'm not going to be as perfect but I am close to it."

Figure 96: When Marie experiences severe pain she tucks herself into a fetal position because the compactness helps to reduce pain. She drew her nerves because “they are on fire and they are in a lot of pain.”

Some participants expressed self-efficacy by their bodies' overall positions and dress. For example, Geraldine explained that fashion was a medium for empowerment.

> I do love fashion, but I don't use fashion because I love fashion. I use the red glove and my red lipstick and my jewelry because I need it to help me to look in the mirror and say, "it's okay, you are okay." Um, you can appear normal. You can try again today no matter if yesterday was bad.

Figure 97: Geraldine explained that to feel better she "put on that red glove, put on that lipstick. Let's try it again today, let's see where it takes you."

In comparison to Geraldine's red glove, Angelina drew red shoes to symbolize her "burning desire" to resist the confines of FM. Angelina explained she could no longer wear high heels because of pain and mobility issues. However, she painted red ballet flats to highlight her passion and personality.

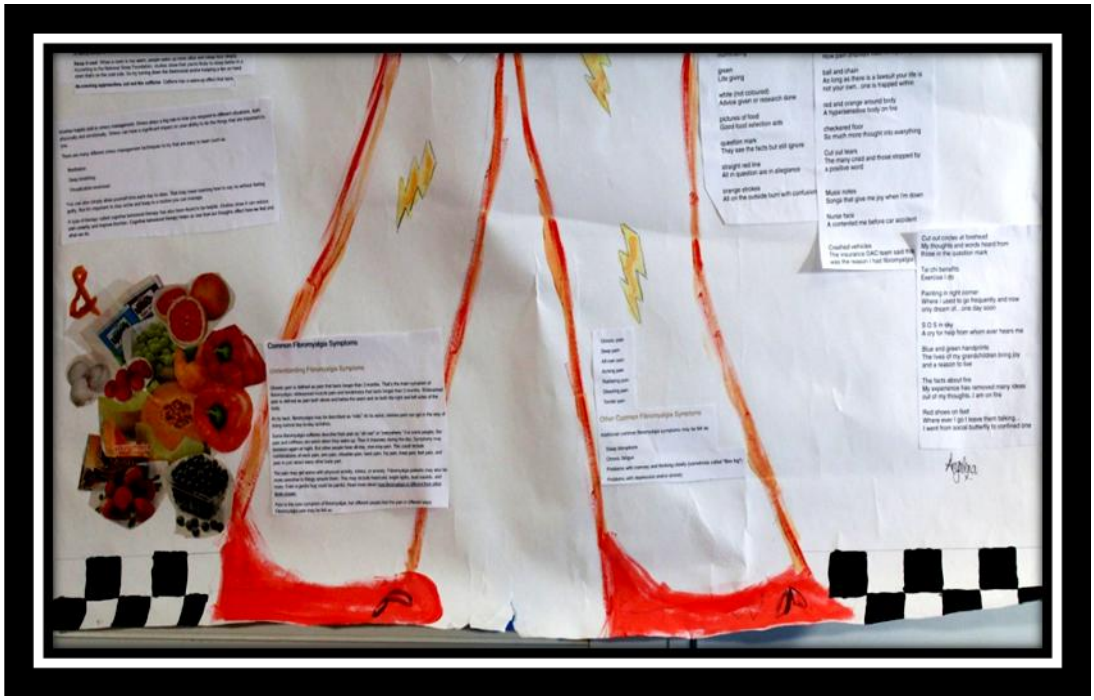


Figure 98: Angelina stated, "And now I'm kinda like confined… And there's burning desires in these feet!"

Spirituality

In addition to advocacy and education, self-care and self-efficacy, many participants embraced spirituality as a form of self-management. Participants expressed different forms of spirituality, ranging from faith in God to beliefs about the power of the

natural world. In their body maps, participants represented spirituality in images of nature (e.g. sun and sky), religious symbols (e.g. crosses), and biblical quotes. Despite different faiths, participants shared a common belief that their corporeal beings were connected to a greater power, which supported them in managing FM and its accompanying stigma. For example, Phoenix reported that she found strength by trusting her intuitions and God.

> …you have to trust your instincts because a lot of the time you're right. …for me scripturally it's trusting in God, I have a favorite scripture that I kind of have made my mantra: "Trust in the Lord with all your heart and lean not on your own understanding and all your ways acknowledge him and he will make your path straight." You know holding on to that, you know everything is lining up slowly.

In comparison, Weezie explained that she learned through God's teachings that her life had purpose; although she was unable to perform paid work, she realized she could contribute to society in other ways.

> With His power I am able to do quality things every day... I will reach out to encourage someone else who needs comfort or understanding… In this way, I too will be doing important work on this earth and will not suffer the feelings of loneliness or inferiority because I can't work in the same way as most of my peers. I'll be contributing to the world in a meaningful way.

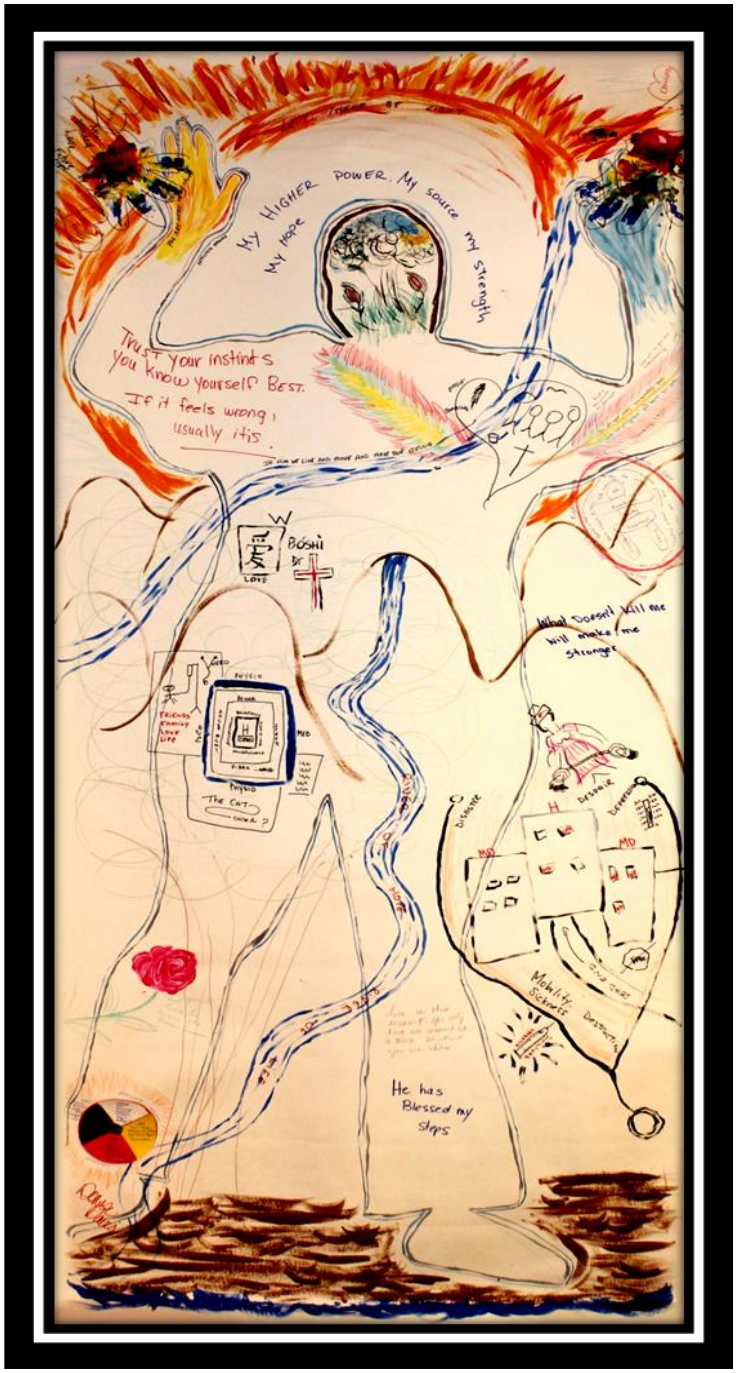


Figure 99: Phoenix's body map exemplifies holistic spirituality with symbols from aboriginal culture and nature. Phoenix drew a river winding around herself, embodying "the river of hope, the river of life, it reminded me, right of who I was and the strength that I have within me and even though I thought I was going to die, emotionally, mentally, physically it actually made me a stronger person."

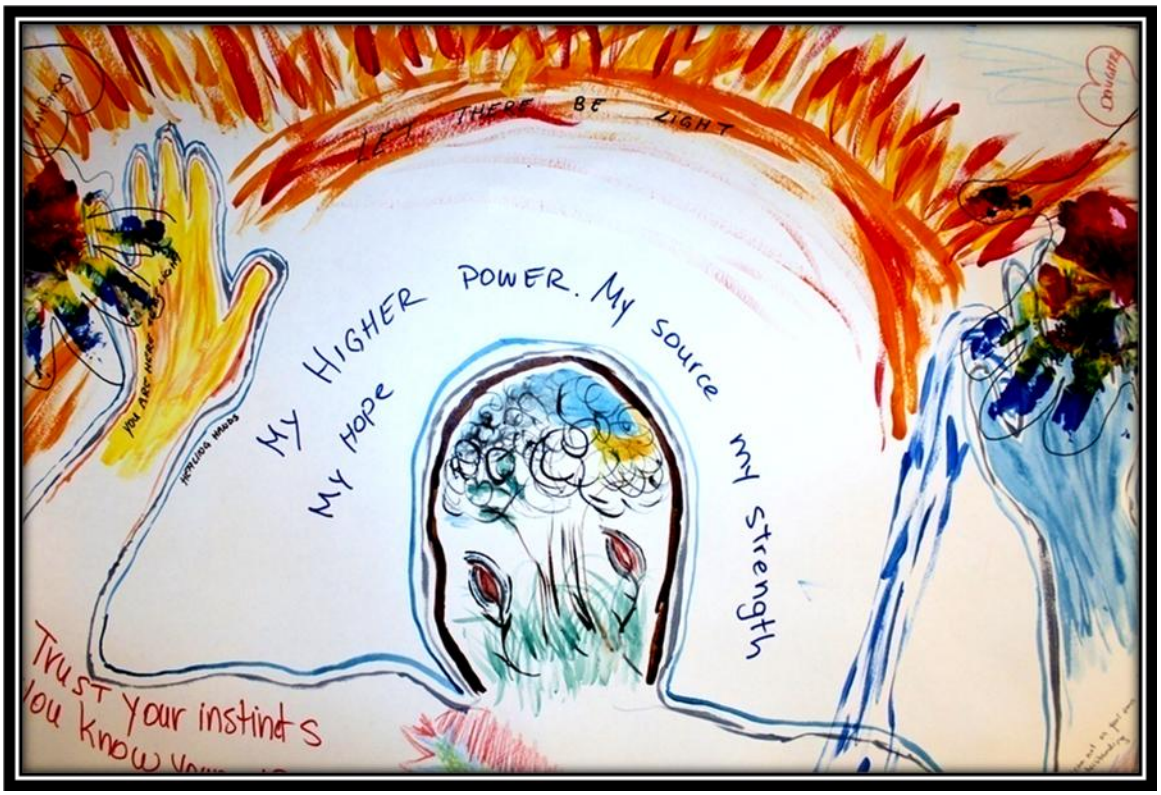


Figure 100: Phoenix stated "inside I believe in hope and faith and I believe that I can do things with Christ who strengthens me."

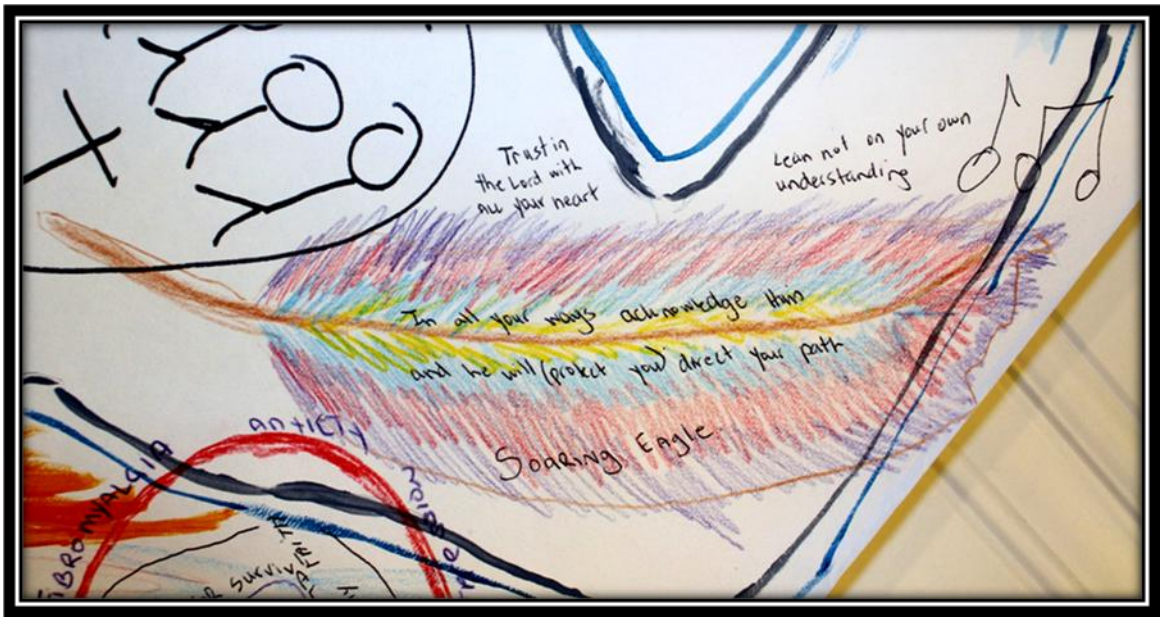


Figure 101: Phoenix explained that "someone give me a sacred eagle feather… it was really meaningful to me… and reminds me of the strength of an eagle and I think that is where my soaring eagle comes from. It's protection… biblically it means a lot spiritually..."

Figure 102: Anna explained the connection between her identity and church involvement.

> The yellow hand is this is what I used to be, I guess and this is what I've become …I used to be very outgoing, very social, always involved in lots of things… people used to describe me as being a light. At work, I was always able to focus on things. I am very involved in my church as well. I've always been involved...

Figure 103: Saint Augustine believed spirituality and identity were connected. He stated: "if you have some people to hold you up, or – you can anchor yourself too. Your faith – first of all I think you have to have the faith within your strong self."

Chapter Summary

In this chapter, I have reported the findings about participants' strategies for resisting the chronic confines of FM and the system of compromised healthcare. Although many participants reported utilizing similar strategies of resistance, they implemented and practiced these strategies on an individual basis. In the next chapter, I move from the topic of individual resistance to collective resistance by exploring participants' strategies for transforming the existing system into a system of uncompromised care.

CHAPTER EIGHT – FINDINGS

EXPERIENCES OF AND VISIONS FOR UNCOMPROMISED CARE

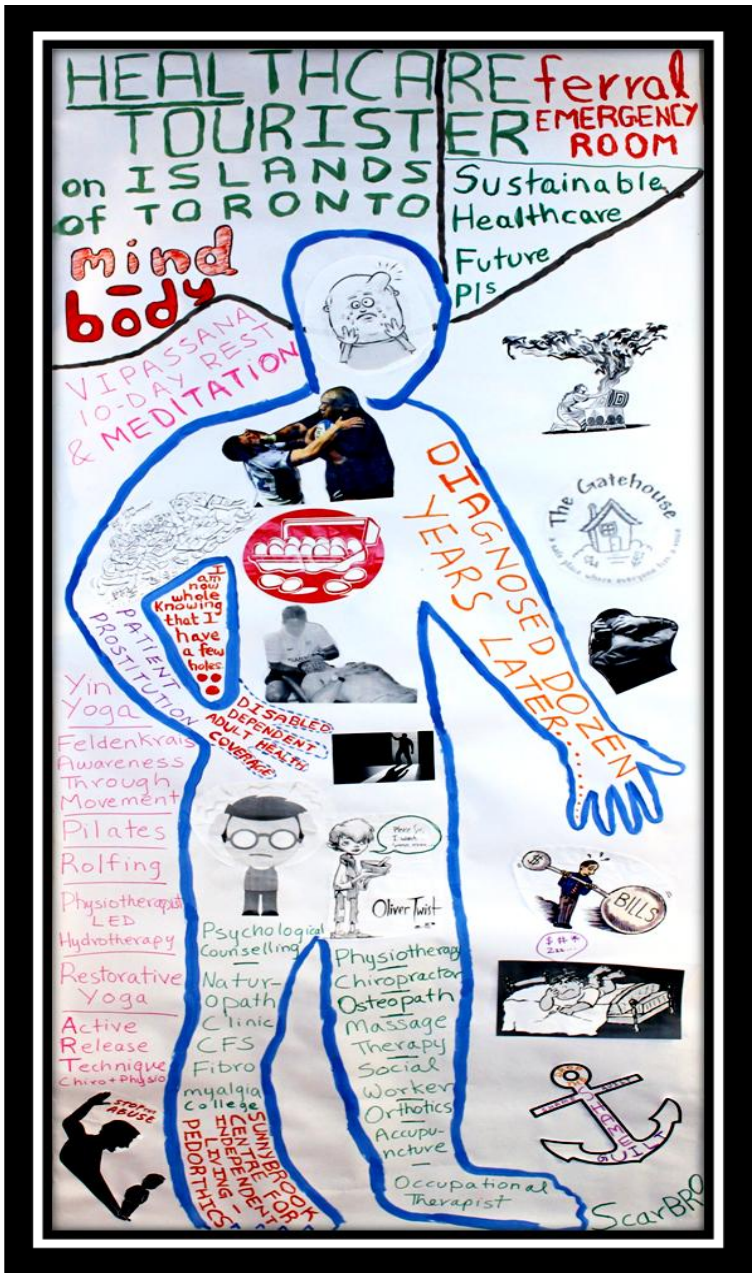


Figure 104: Scarbro stated in the healthcare system "there's a lot of support in keeping somebody in a wheelchair but there's no support in helping somebody get out of it." He analogized that like patients with FM, Ontario's healthcare system was suffering from the symptom of fatigue and "needs to take some rest and… Reconsider itself." What could reconsideration look like?

I have introduced this chapter with Scarbro's body map. At the top of his body map, Scarbro wrote a request for a "sustainable healthcare future, please." This chapter addresses what a sustainable healthcare future could potentially look like for people with FM, builds on the findings reported in the previous three chapters, and has a threefold purpose.

In chapter five, I reported that the majority of participants' experienced compromised healthcare, but I strategically excluded participants' accounts of clinical practices that they considered helpful; I did not want these themes about helpful healthcare practices to be overshadowed by the darker themes of compromised care. Consequently, the first purpose of this chapter is to report the findings about participants' narratives of positive patient-provider interactions. The second purpose of this chapter is to outline how the qualities of caring patient-provider interactions could be utilized in the development of best practice models for FM care. The final purpose of this chapter is to report participants' suggestions for improving existing healthcare services and creating an innovative system of uncompromised healthcare for patients with FM.

Positive Patient-Provider Interactions

In this study, the majority of participants reported experiences of compromised care. However, three participants reported experiencing solely positive patient-provider interactions. All three participants were white, middle-class women who spoke articulately. In comparison, some participants reported experiencing a combination of positive and negative patient-provider interactions at different points in their healthcare journeys. These participants embodied differences such as gender, age, race, culture, and class. Although these two groups of participants -- who respectively described solely positive interactions and

mixed interactions -- had demographic differences, they shared similar qualities: they expressed gratitude about life, senses of humor, and positive attitudes.

Participants' narratives illuminated that positive interactions with healthcare providers consisted of ongoing relationships based on comprehensive care. In these relationships, providers were open to collaboration, being held accountable for their actions, legitimizing FM, spending time to actively listen to and teach patients, as well as engaging in a therapeutic rapport. Another aspect of these relationships involved the participants' role in maintaining a positive attitude.

Qualities of Caring Relationships

Comprehensive care.

As previously reported, many participants who experienced uncaring interactions did not receive adequate diagnostic and treatment services; as a remedy, some participants had to advocate for themselves, as well as assume responsibility for educating providers about FM. In comparison, all participants who experienced positive patient-provider interactions reported that they received comprehensive care. For example, Fanny Freckles described that her family doctor assumed responsibility for ensuring accurate diagnoses and legitimized her need for frequent appointments.

> Anyways my doctor has been wonderful, I still present with different symptoms and he still will test me for those symptoms to see what might be causing them. At one point, I said to him "I'm coming back to you all the time with all these symptoms and we are finding nothing." I said "I really feel like I'm wasting your time" and he said "that's my job." He said "it's not your job to assume it's your fibromyalgia, it's my job to figure out whether it is your fibromyalgia." …he said "you have fibromyalgia

> but you can have anything else too." He said "that's my job to figure out what it is, and if it is fibromyalgia, fine, but I'm going to make sure." So I have an awful lot of confidence in my doctor, that's my family doctor. My rheumatologist not so much though. The other day I had a problem with my shoulder and I went to him and he said "well I can't tell the difference whether it's your fibromyalgia or something else" and that was it. I said "thank you."

Fanny Freckles' narrative reveals that her doctor did not dismiss FM as a wastebasket diagnosis, and instead he displayed a commitment to correctly diagnosing co-morbid conditions. In comparison to the family doctor, Fanny Freckles' rheumatologist appeared unsure, indifferent, and even apathetic about her symptoms.

Collaboration and accountability.

Similarly, Weezie reported that her family doctor was committed not only to providing comprehensive care, but also to being held accountable for her own behaviors.

> My overall health care experience has been very positive, the condition I had was unknown and my systems appeared twenty years so I can't blame that on a doctor, most just didn't know about this condition. My understanding is that today there are some doctors that refuse to acknowledge this syndrome exists and some that have no training in dealing with it. It was very helpful to me that my doctor asked me to tell her that if I ever felt she was treating me like someone who had too many symptoms and therefore without merit, not to be afraid to bring it to her attention as this can happen often with patients with fibromyalgia. There are so many body systems affected and so many transient symptoms that can overwhelm even a seasoned practitioner.

Weezie's doctor displayed openness to constructive feedback, thereby creating a reciprocal relationship in which power was shared between provider and patient.

Legitimizing FM.

An underlying theme in both Fanny Freckle and Weezie's narratives was the legitimation of FM. The importance of legitimacy was highlighted by Marie who was willing to travel every few months outside of Ontario in order to meet with medical specialists who provided supportive care.

> I have my pain treatment specialist and my neurologist in [a city in a different province] because they have been super big supporters or big believers in fibro and they never made me feel like, you know, I'm crazy or that my symptoms aren't real. They have a legitimate interest in wanting to make sure that I feel better. They do everything that they can and they are much more, I guess, sympathetic compared to other medical professionals that I've dealt with; like you can tell they genuinely care, rather than [saying] here "I'll just give you pills and then you can go away." They are really good in terms of knowing… that if I'm given a medication, I'm going to research it first [laughs].

Figure 105: Marie explained that the lighthouse represented her medical specialists because they were her beacons of hope.

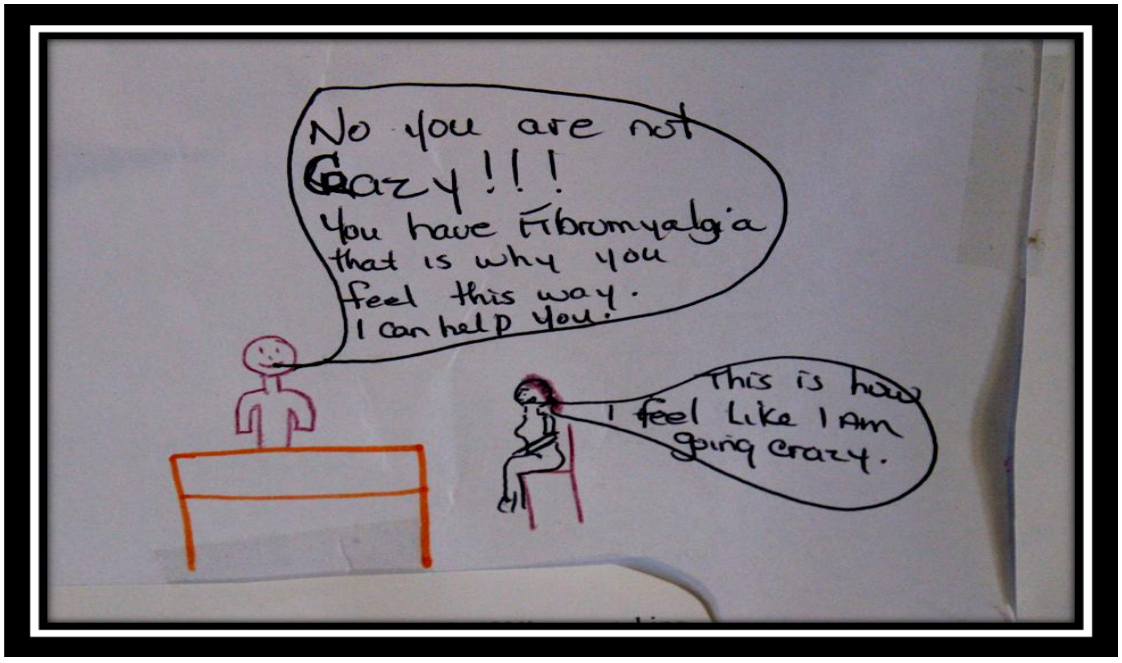


Figure 106: Snay depicted her family doctor stating, “No you are not crazy!!! You have fibromyalgia – that is why you feel this way. I can help you.”

Figure 107: Evelyn stated, “I found a good doctor, finally, and she made me feel like, you know, get on with life, be good, people were listening to me.”

Spending time with patients.

In addition to being held accountable, some participants reported that supportive providers’ spent time to actively listen, gather clinical information, and address patients’

questions and concerns. For example, Rare Gem explained that during an appointment her doctor spent an hour asking and answering questions.

> She took an *hour* to talk to me and she answered my - *all* the questions. And then I asked her lots of questions. I was worried [and] she says "don't worry about it". And she [doctor addressed all of her concerns and inquired about] …this thing and how about what happened and how it happened and why I feel that.

Participants reported that providers spent time to actively listening to patients, as well to provide both practical and emotional support. For instance, Sarah explained that providers "who were good" taught patients about self-management.

> When… you encounter an unhelpful medical professional and there are a lot of them that have attitude and they just want to dump on you and dump you out, and so my experience was when I found people who were good, it's like they want to help you… they help you manage things and do things a little bit better, not necessarily a cure, but trying to at least function again.

Weezie described that the time her naturopath spent with her led to both emotional and physical healing.

> I tried a number of different [allopathic] therapies over the years… but most had terrible side effects or worse, no effect at all. Then I met my naturopath. She was a godsend to me, she listened to me, she heard me, she believed me. She let me cry when I hurt, she rejoiced with me when I felt better, she taught me how to change the negative messages I was giving to myself and find my own strength hidden under the oppressive symptoms that had threatened to consume me. She helped me to recognize all that I had to be thankful for [which was] so much more than I had realized. She

> helped me to find purpose and meaning in the things that I could still do and to let go of that which I couldn't.

Weezie's narrative highlighted that the time her naturopath spent with her was productive and multi-purposed. Weezie's self-confidence and sense of self-efficacy was improved by the naturopath's legitimation of her experiences, celebration of her gains, and training in mindfulness techniques.

Therapeutic Rapport.

In addition to Weezie's healing interactions with a non-medical doctor, other participants reported experiencing a therapeutic rapport with other allied healthcare professionals. Participants' narratives of therapeutic rapport highlighted how providers fostered safe environments based on mutual respect, empathy, and trust. For example, Saint Augustine described how his psychotherapist both believed in him and in the reality of his condition. He also explained that they both experienced a process of personal growth due to the power of their rapport.

> When I go in and see her I would talk for the forty-five minutes or whatever and then there would be sometimes where she would start crying. She said to me that she had never had a patient that made her cry. I asked her why, and she said because I have so much fight in me, so much things living within me that she gets inspired… hearing that also makes me feel good that I'm contributing something... She believed in me, she made me believe that whatever is happening is real and whatever anyone else says to not worry about them.

Figure 108: Saint Augustine represented his healthcare team as a hand; like fingers, each team member was invaluable, served a specific function, and could not operate at capacity if another member was missing. He explained that his psychotherapist was central in building his healthcare team: "I put her in the middle here [of his hand] because she was the one who started to get connected to the other doctors that support me…"

Figure 109**:** Snay explained, “This is my family doctor with all of my medications and… I’ve put him up on a pedestal because he’s not only my family doctor - he’s my counselor, a friend... He belongs on a pedestal as far as I’m concerned.”

Positive attitudes.

In addition to providers' supportive roles, several participants reported that they themselves played a role in experiencing positive interactions. For example, Peanuts explained that her healthcare experiences "have all been positive: always been positive. I haven't had any negativity with my fibro." Peanuts partly attributed her positive experiences to her doctors' legitimation of FM. She stated, "I've had good experiences, I've never had anybody say, 'it's all up there in your rectum' [laughs]. Crazy things like that. No I've never had. I have a good family doctor." During further discussion, I asked Peanuts, "Why do you think your health care experiences have been primarily positive?" She replied, "Because I am a positive person… Because I always have been."

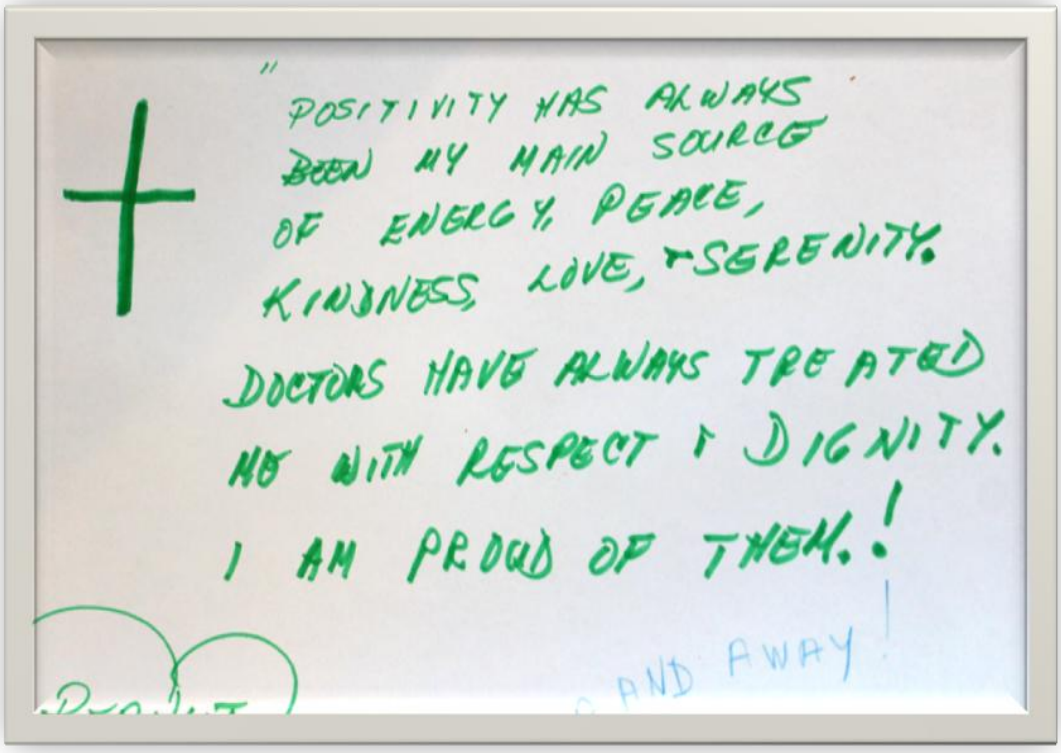


Figure 110: Peanuts explained, "…positivity has always been my main source of energy. Peace, kindness, love, serenity. Doctors have always treated me with respect and dignity. I am proud of them."

Figure 111: Brian illustrated that he was currently in a positive place in his life. Brain described that his support system, including his naturopathic doctor and his family, contributed to his sense of wellbeing.

Learning from Positive Patient-Provider Interactions

Participants' narratives of positive interactions reveal that the healthcare system is not completely compromised. Participants experienced positive interactions when they received comprehensive care based on providers' abilities to: collaborate, be held accountable for their actions, legitimize FM, spend time with patients, and foster a therapeutic alliance. Furthermore, positive interactions were enhanced when participants maintained positive outlooks. All narratives of positive interactions had a common theme: participants experienced legitimizing attitudes from providers. This finding illuminates that a prerequisite for system improvement involves replacing the meta-discourse that FM is *illegitimate* with the discourse that FM is *legitimate*. In addition to changing the discourse, structural changes are required. In the following section, I report participants' suggestions for promoting structural changes.

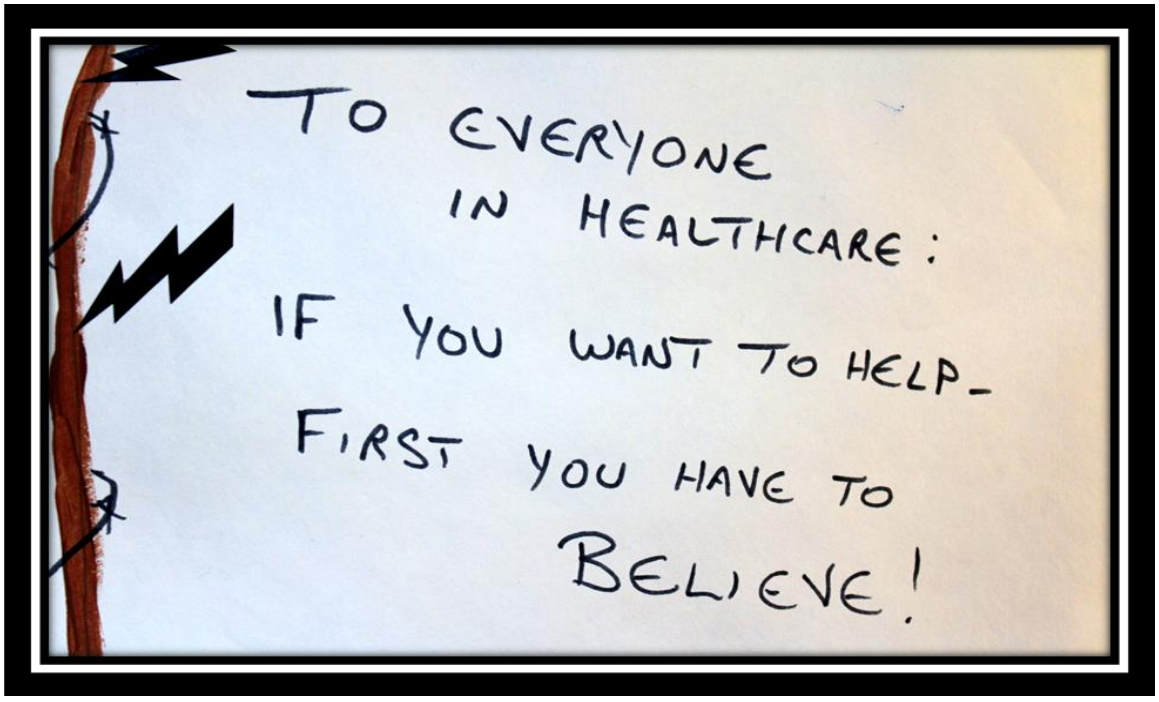


Figure 112: Lori illuminated that the first step towards healthcare change is belief in FM.

Strategies for Change

The majority of participants shared strategies for changing the healthcare system. They envisioned that care for the FM patient population should be patient-centered, transdisciplinary cost-effective**,** integrated, holistic**,** and centralized. They also emphasized of importance of increasing knowledge about FM by promoting research.

Figure 113: In her body map, Geraldine repeated the path motif to convey hope.

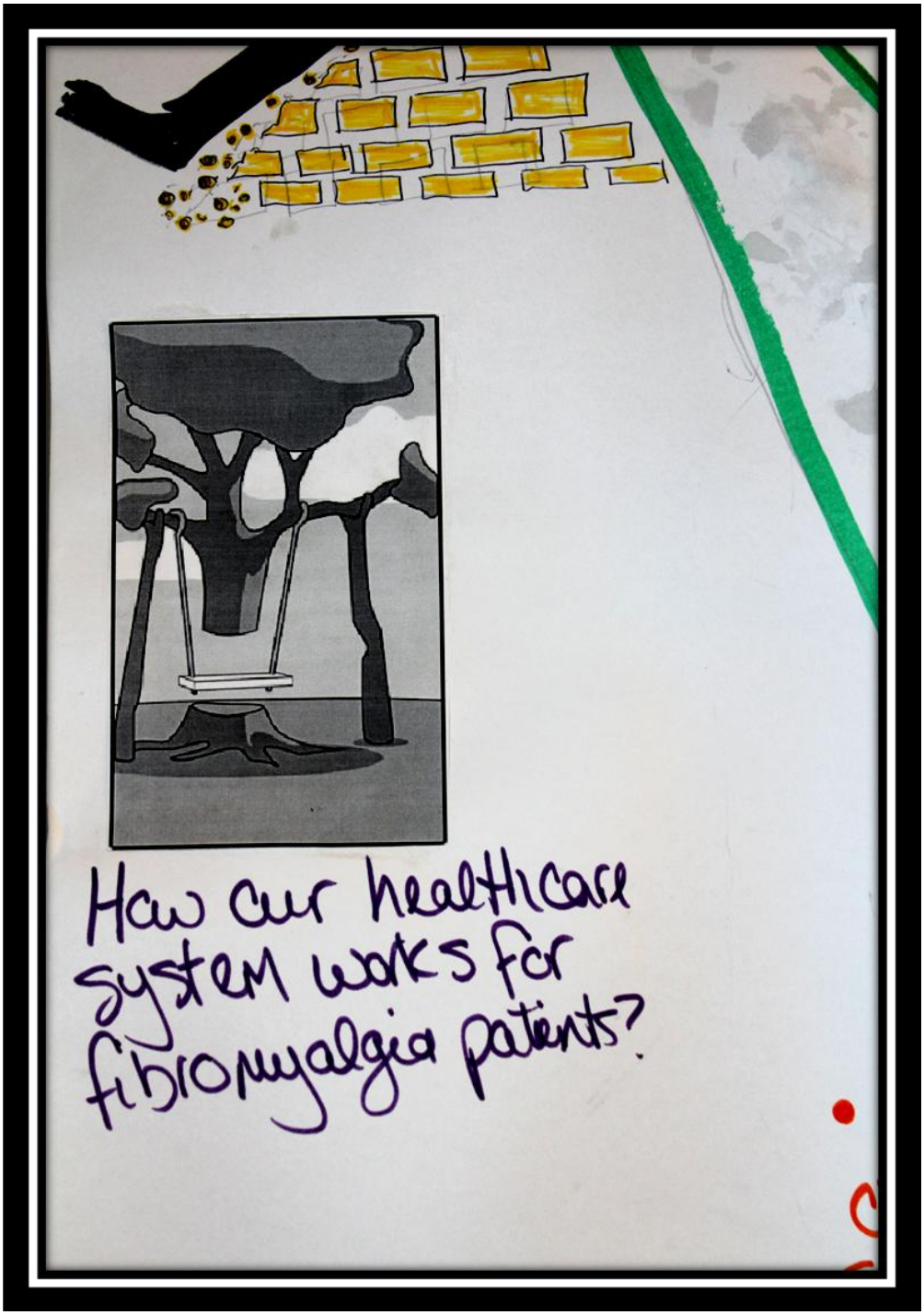


Figure 114: Sarah illustrated a broken healthcare system with the graphic of a swing hanging unsupported from a tree that is missing part of its trunk. She rhetorically asked, “How our health care system works for fibromyalgia patients, right? Because it is true, it is this bizarre thing [healthcare is like the tree] that shouldn’t be able to stand up but, and probably won’t for much longer.”

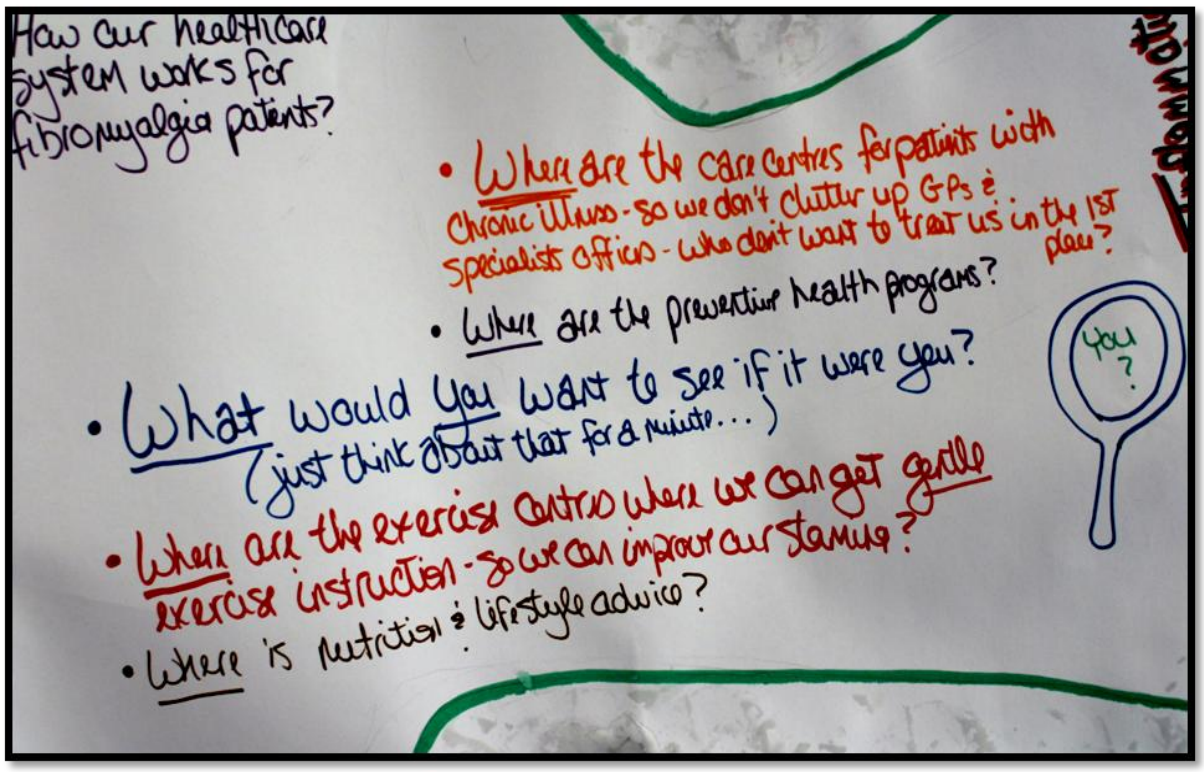


Figure 115: In order to stimulate thought about healthcare change, Sarah asked the following questions.

> I asked where are the care centers for patients with chronic illness? So we don't clutter up GPs and specialist offices who don't want to treat us in the first place. Where are the preventative health programs? What would you want to see if it were you? Just think about that for a minute. So I put a little mirror here with a "you" so hopefully they [providers] will look at that.

Patient-Centered Care

Many participants reported that the current healthcare system was not patient-centered. They experienced feeling at the mercy of doctors who did not believe they were ill. Participants envisioned patient-centered care as an environment in which they collaborated

with providers to develop comprehensive and individually-tailored healthcare plans. For example, Hope analogized that patients were like retail consumers shopping for pasta sauce; consumers required a variety of products to accommodate their different tastes.

> …there is this person… he was asked by Prego Spaghetti Sauce "why my product is better and everything is better but I'm not out selling Ragu?" Because he said "we are looking at it a different way. We are trying to make a certain product to please everybody" but what he is trying to say is we have to create things that fit everybody… Prego at that time only had a certain number of products, but now they have sixty different kinds of sauce because we are more than three kinds of people; we are like different kinds of people… the medical field has been pegging us the way they want to see us. They have to merge together in order to cater to us [who] really have the problems in order to go forward and not be a burden to the medical system or to the society - that we can be healed so that we can still continue to contribute positively instead of being pegged as disabled and unable to work and continue anymore….

Hope's narrative highlights that one of the objectives of individually-tailored care is to promote recovery, thereby enabling people with FM to "contribute positively" through employment and other activities.

Transdisciplinary Care

Many participants described that patient-centered care involved patients being active members of transdisciplinary healthcare teams. Participants reported that transdisciplinary providers were helpful because they contributed different perspectives, approaches and skills, thereby enriching patients' abilities to learn new self-management skills. Sarah hypothesized

that group-based transdisciplinary programs could be less costly than individual medical services.

> …it makes me think about health care management because a lot of things that could be helpful are cost effective; they are not expensive… like nutrition, lifestyle and helping with what kind of exercises that we need and all of that. You could have a lot of people you could treat at once; you don't have to have individual appointments....

Figure 116: Evelyn explained, "The road to recovery: you need to build a team and a support network and join a local support group."

Integrated and Holistic Care

Participants described that transdisciplinary programs were crucial for moving beyond the Cartesian dualism of the medical model and providing an integrated approach to the whole patient: mind and body. For example, Lori reported that for the first ten years of her healthcare journey she was informed by doctors that she required psychiatric treatment because they could not identify a physical etiology for her FM symptoms.

> I'm sorry but a doctor needs to think outside the box, a doctor needs to recognize that there is more then he has read in his textbooks. They just weren't prepared to do that. I have a good doctor now, but she still - although she recognizes what I have and she is trying to be as supportive and helpful as possible, I come in with a new symptom, and she says "go see this specialist." Everything is isolated, everything is a piece at a time, and nothing is holistic. Look at who I am as a person and what's happening head to toe. I think that does all of us a huge disservice I think it, puts us in a category of being symptoms rather than of having a syndrome or a disease that attacks multiple things and I think until they've got that figured out… we are going to continue to have problems.

Some participants reported that they found holistic and naturopathic approaches more helpful than the silos of services within the medical model. For example, Scarbro recounted that finding naturopathic care specialized in the management of "chronic fatigue syndrome and fibromyalgia… was the biggest step because I think that's the *one single place* that totally understands what chronic fatigue and fibromyalgia is… they understand the whole picture. So, that's pretty powerful."

Figure 117: Hope's tree and branches represented interconnection: "I want the Western medical or the normal traditional medical field to merge with the non-traditional."

Centralized Care

Some participants envisioned integration as a centralized healthcare centre devoted to the FM patient population. At the top of his body map, for example, Scarbro wrote, "Healthcare Tourister on the Islands of Toronto." He described feeling like a tourist waiting "for information to travel from one island to another".

> [I]t took months for a file to get transferred…the island just describes like…even if it's being referred to one hospital to the next or one organization to the next, within the OHIP system um…the reason I use islands is because it takes months and a lot of follow up and effort to just get things moving or referred or…

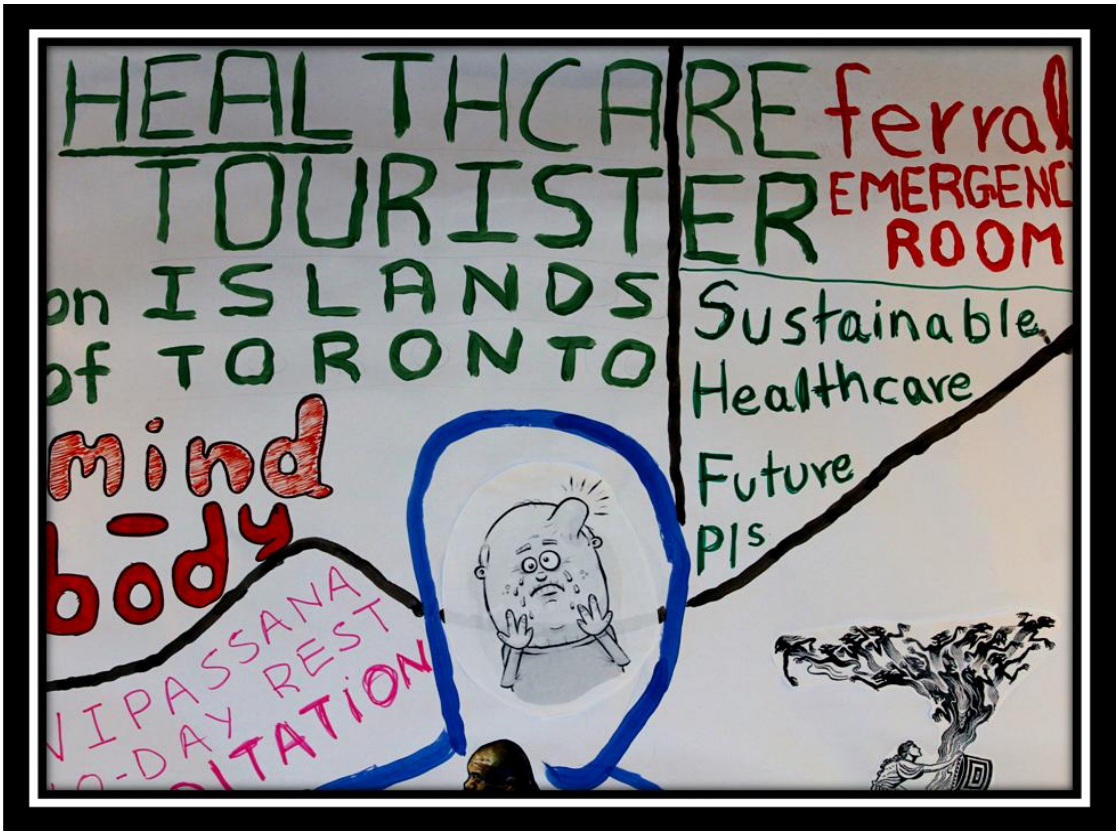


Figure 118: Scarbro underlined the word "heal" in "healthcare" in order to emphasize that patients required centralized service. He stated, "I think the future of healthcare is going to be centered around hospitals and clinics and the way the system is set up.

Similar to Scarbro, Rare Gem envisioned a "fibromyalgia center" that was a "complete centre" integrating both allopathic and CAM providers. Rare Gem's vision was based on the healthcare system in India, her country of origin.

> [In Canada] Heart specialists have nothing to do with the endocrinologist. Endocrinologist has nothing to do with [the] neurologist. Doesn't matter, you should all sit together and talk to each other: "I have this patient and this is what's happening." Back home, doctors' talk together. They share. And then they come up with a plan.

Promoting Research

Some participants discussed that research on FM was a key strategy for altering public perceptions and healthcare providers' attitudes. For example, Lori expressed hope that this research study would contribute to change.

> I am very happy to be part of this group. I think that ultimately the work that you are doing is going to make a difference to the medical community which is where we need that difference to be made. Because right now, they [medical community] just don't know who we are. They don't know who we are or what we need and they don't seem to be terribly motivated to find out. I think this is a really good step in the right direction and it always makes me feel much better to be able to talk to people who are in the same place that I am…

Lori's narrative demonstrated that body-map storytelling as a methodology had the potential to promote social change, but the focus group sessions had already contributed to personal change by fostering community and reducing isolation.

Figure 119: On her body map, Angelina explained that she "put the colleges and universities and I said 'are they catching up?'

Chapter Summary

In this chapter, I reported the findings related to participants' positive healthcare experiences and their suggestions for improving healthcare services. These findings provide a road map of practical strategies for developing a system of uncompromised care for patients with FM. These findings also suggest that change to the current state of healthcare is essential. Participant, Snay, summarized this challenge in the following body map picture.

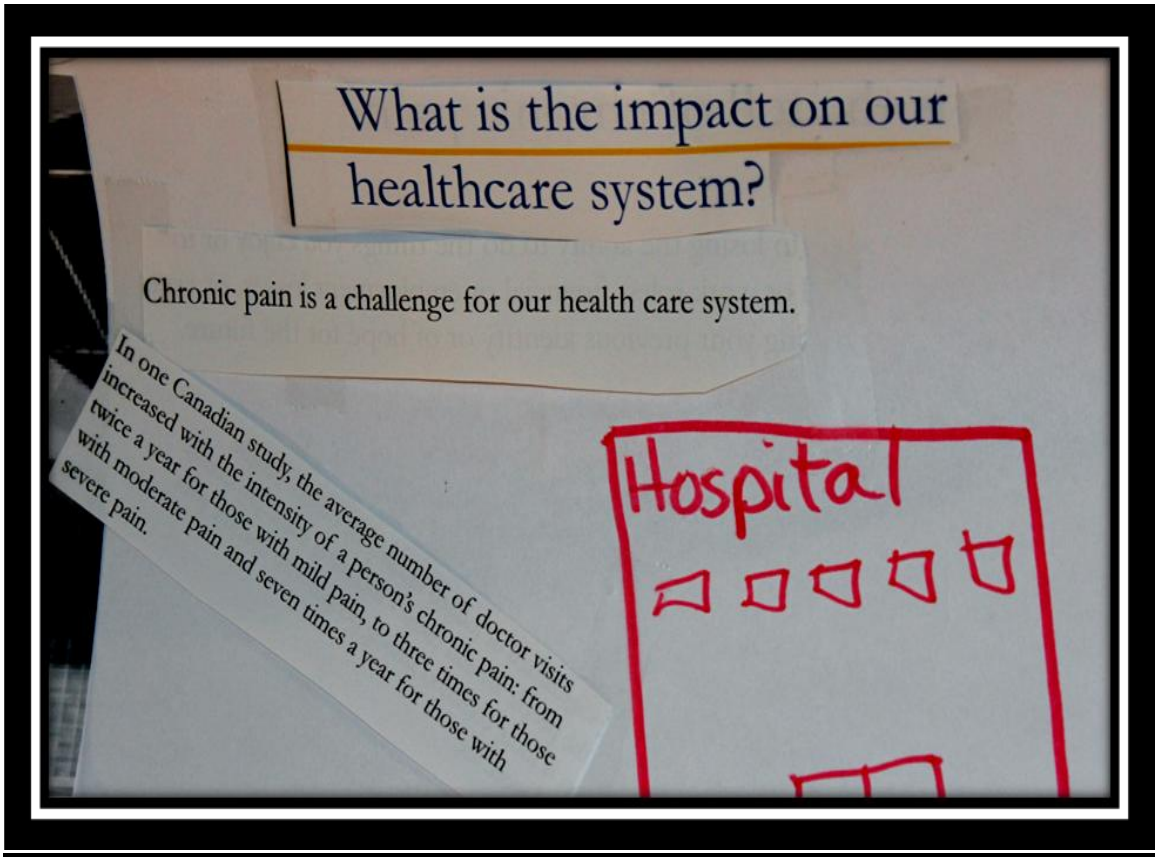


Figure 120: Snay displayed facts about chronic pain.

Chronic pain is a challenge for our healthcare system. In a Canadian study, the average number of doctor visits increased with the intensity of a person's chronic pain; from twice a year for those with mild pain, to three times for those with moderate pain and seven times a year for those with severe pain.

CHAPTER NINE – DISCUSSION OF FINDINGS

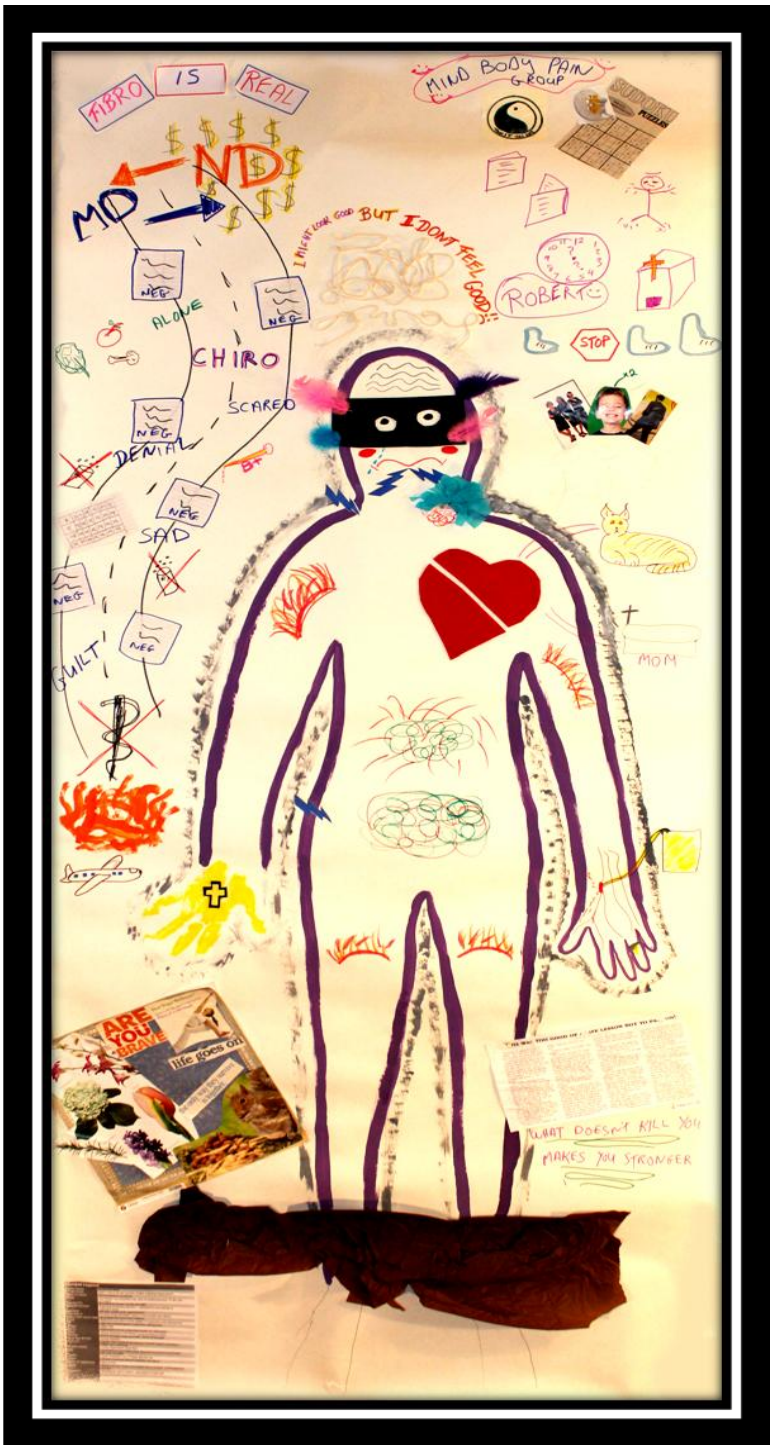


Figure 121: Anna's body map.

I open this chapter with Anna's body map because she illustrated several of this study's key findings. Anna portrayed her healthcare journey as a winding road of negative test results and costly treatments. She also displayed the struggles of living with FM; she wore a mask in public, had a broken heart, and used brown tissue paper to depict feeling stuck in the mud. However, she utilized self-management strategies, including pacing her energy, reading, and church involvement, to resist the confines of a contested condition. Like Anna's body map, this chapter weaves together the primary findings of this study. In this chapter, I discuss the grounded theory that emerged from the data analysis, intertwine the relevant literature with the study's findings, outline the study's implications, and conclude with suggestions for future directions in the area of FM research.

A Grounded Theory of FM and Compromised Care in Neoliberal Society

Participants' verbal and visual representations of their healthcare experiences revealed a kaleidoscope of intrapersonal, interpersonal, and institutional contexts. Regarding the intrapersonal context, all participants described that after the onset of FM they had to reconcile their pre-illness identities with the realities of living with a chronic condition. Within the interpersonal realm, all participants reported that living with FM impacted their relationships with families, friends, employers and healthcare providers. Institutionally, most participants described the challenges of accessing healthcare services due to systemic barriers such as a lack of both resources and continuity of care. Within these intrapersonal, interpersonal, and institutional contexts, participants repeatedly experienced the discourse that FM was an illegitimate condition.

The inextricable linkage of the micro and macro-level contexts led to the development of a theory about the interface of identity politics, healthcare interactions, and social norms. This grounded theory is illustrated in the following Venn diagram.

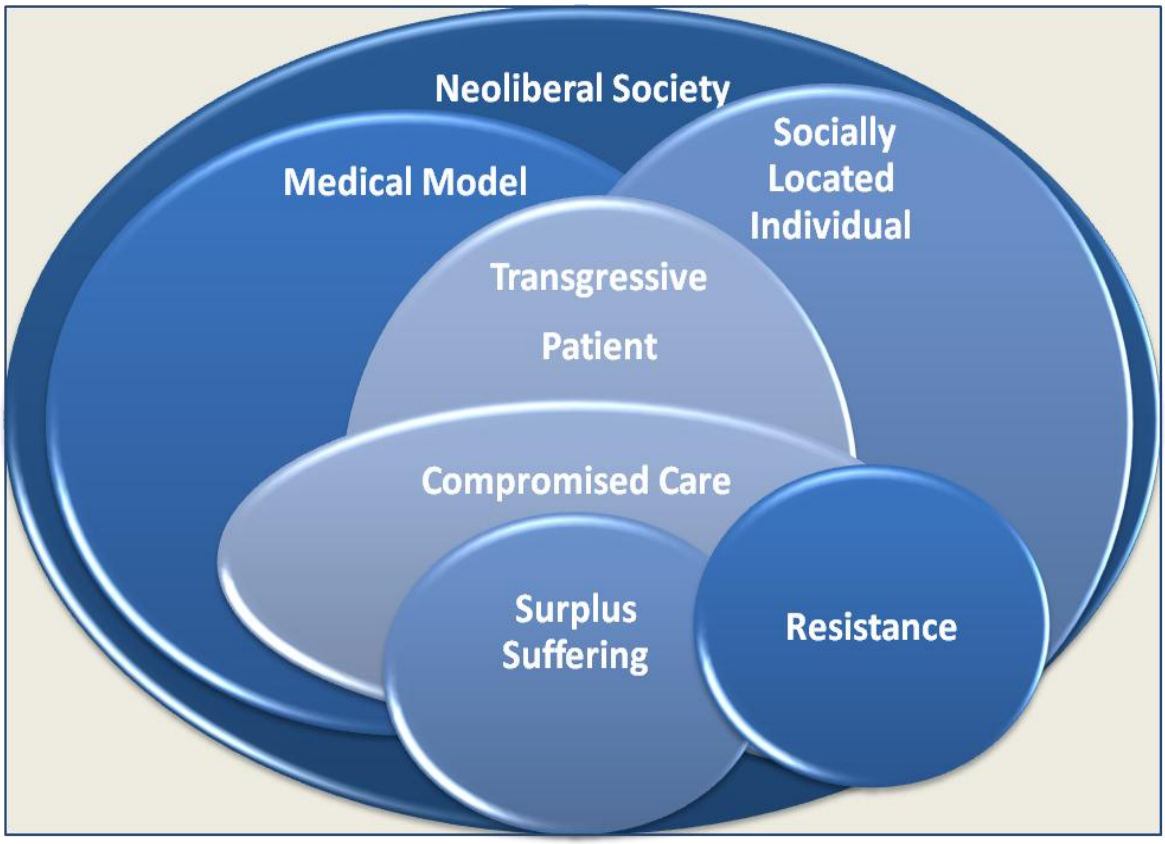


Figure 122: A Grounded Theory of FM and Compromised Care in the Neoliberal Society.

In this diagram, the largest circle represents the ***neoliberal society***. Participants' experiences of interactions with healthcare providers cannot be understood without taking into account the sociopolitical context of the neoliberal society. Neo-liberalism is an invisible

system of power based on the values of rationality, hyper-individualism, and personal responsibility, as well as the belief that governments should have limited influence in the lives of individuals (Ayo, 2012; Clarke, 2012). These values and beliefs both overtly and covertly govern individual experiences, interpersonal interactions, and social systems (Ayo, 2012).

The power of neo-liberalism lies in the fact that this system of discourses, beliefs, and values is simultaneously everywhere but never seen (Ayo, 2012). Because of this invisibility, institutions and citizens operate within bio-looping relationships, internalizing neoliberal discourses, values, and beliefs that have become embedded as taken-for-granted knowledge. These bio-looping relationships highlight the intersectionality of all micro- and macro-level processes.

On the macro-level, one of the social systems oxygenated by neoliberal values is the allopathic ***medical model***. The allopathic medical model is a labyrinth of primary and secondary healthcare services focused on the medicalization of mind and body (Conrad, 2007). This model is based on the positivist "model of science" and is characterized by "attributes such as objectivity, precision, certainty (within a specific degree of error), generalizability, quantification, replication, and causality" (Clarke, 2012, p. 213). These attributes reinforce the medical model's status as a system of superiority bestowed with the authority to clinically gaze at and attach meaning to people's minds and bodies (Clarke, 2012).

The medical model operates on the assumptions of mind-body dualism, physical reductionism, and "specific etiology" (Clarke, 2012, p. 213). The assumption of mind-body dualism, which was developed by Descartes, underlies the medical model's practice of

viewing the mind and body as unrelated entities. Mind-body dualism enables the medical model to physically reduce and segregate illnesses/diseases based on the location and types of symptoms (Barker, 2002; Crooks et al., 2008). The medical model physically reduces symptoms in order to sort patients into specific medical specialties. In turn, these medical specialties become responsible for governing patients through diagnosis and treatment (Album & Westin, 2008). The process of diagnosis perpetuates the assumption that the etiology of illnesses/diseases can be seen within the body. Diagnostic procedures, including physical examinations, imaging, and blood work, confirm either the presence or absence of illness/infection/disease. The visual presence/absence of pathology is associated with assumptions about legitimacy/illegitimacy, thereby impacting how patients will be subsequently treated in both a clinical and relational sense (Haugli et al., 2004; Wainright et al., 2006).

Individuals do not exist in isolation. On the contrary, they are ***socially located*** within complex and distinctive cultural, historical, socioeconomic, and geographic contexts. When socially located individuals experience symptoms they enter the medical model and assume the role of patients (Parson, 1951). Within the medical model's positivist diagnostic paradigm, patients who fit into prescribed and acceptable categories of disease are rewarded and validated by having their illness experiences and identities legitimized (Hazemeijer & Rasker, 2002; Smith, 2002). Conversely, patients, who do not smoothly slide into diagnostic categories, collide with the expectations/rules/norms of the medical model (Crooks et al., 2008; Smith, 2002; Ware, 1992). This study has conceptualized that within the medical model participants became covertly labeled as ***transgressive patients***. These patients collided with the medical model because the model was neither designed nor equipped to effectively

understand, diagnosis, treat, and manage conditions of unknown origin. This collision leads to a system of ***compromised care***.

Based on this study's findings, I consider compromised care to be an institutionalized imbalance of power whereby patients with FM, seeking help within primary and secondary healthcare settings, are impacted by structural barriers (e.g. OHIP billing regulations, lack of resources, etc.) and negative interactions with healthcare providers. Negative interactions include providers' discriminatory attitudes and clinical practices (see Figure 123). These findings reveal that the allopathic medical model has failed to provide ethical and equitable care for many patients with FM.

Compromised care is a system of punitive medicine whereby many participants reported experiences of being treated paternalistically, apathetically and, at times, even abusively by providers. These participants described uncaring interactions as emotionally traumatic experiences. This trauma is a form of **"*surplus suffering*"** whereby the stresses of navigating the allopathic healthcare system and searching for diagnosis and treatment were compounded by the distress of being repeatedly dismissed and invalidated by healthcare providers (Clarke, 2014; Clarke, 2013; Clarke & van Amerom, 2007; Clarke & Fletcher, 2004).

As ***socially located individuals***, participants live within varied contexts and embodied systems of differences, including gender, age, class, culture, race, and geography. These differences shaped participants' experiences of compromised care.

Participants described a multitude of differences not only in their social locations but also in their strategies of ***resistance.*** Many participants resisted experiences of compromised care by assuming responsibility for their own healthcare and becoming "entrepreneurial

subjects" whose full-time job was illness management (Robertson, 2001, p. 302). As "entrepreneurial subjects", participants adopted self-management strategies, including self-advocacy, education, seeking alternative forms of healthcare, and engaging in practices of self-care. Participants also reported feelings of empowerment and self-efficacy by harnessing their resilience, inner-strength, and spirituality.

On one hand, "entrepreneurial subjects" can be viewed as "neo-liberal citizens" who unintentionally perpetuated the discourses of individualism and moral responsibility (Robertson, 2001, p. 302). On the other hand, participants can be understood as performing the role of "entrepreneurial subjects" (Butler, 1988) because this was the only way they could find resources and supports within a compromised healthcare system.

Conceptualizing Uncaring Patient-Provider Interactions

Thus far, I have outlined a grounded theory of the ways in which neoliberal values have intersected with medical model policies and practices in order to create and perpetuate participants' systemic experiences of compromised care. I will now describe a theoretical conceptualization about the interpersonal barriers of compromised care: uncaring patient-provider interactions. The following diagram illustrates the components of uncaring interactions.

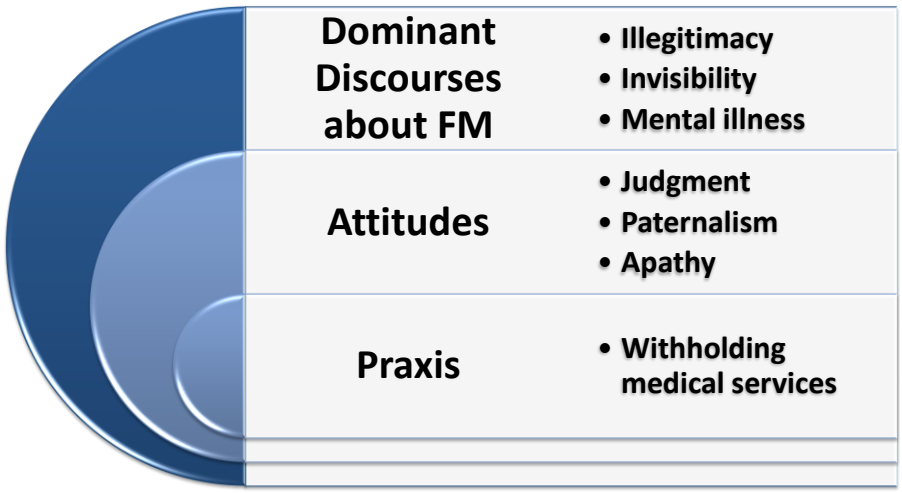


Figure 123: Intersecting Components of Uncaring Interactions.

Participants' narratives of uncaring interactions highlighted three interconnected themes about providers' ***praxis, attitudes*** and ***discourses***. ***Praxis*** refers to providers' clinical process of either giving or withholding medical interventions, including diagnosis, referral, treatment, and illness management. Providers' praxis appears to be influenced by their attitudes about patients with FM. ***Attitudes*** are a nexus of internalized beliefs, values, and moral judgments, which are shaped and reinforced by individual experiences and societal influences. Embedded within participants' reported experiences of providers' praxis and attitudes were ***discourses*** about FM. Specifically, this study found that all participants, who reported experiencing uncaring interactions, were either overtly or covertly informed by providers that FM was an illegitimate condition. The meta-discourse of illegitimacy is rooted

by the positivist assumptions that physical illnesses/diseases are proven via (a) patients' outward appearances and (b) functional medical tests and positive laboratory results. When assumptions (a) and (b) are not met, then assumption (c) follows: the illness/disease is psychosomatic. These three assumptions are based on the binary logic that visible illnesses are legitimate whereas invisible illnesses are illegitimate (Haugli et al., 2004; Wainright et al., 2006).

Potential Critiques of this Grounded Theory

A focus on negative healthcare experiences.

I expect that this grounded theory of compromised care will prompt two possible critiques. First, this theory conceptualizes the dynamics of negative experiences within the allopathic medical model. As such, some readers could argue that this theory sets up binaries between: (a) positive and negative experiences and (b) the systems of allopathic medicine and CAM. As discussed in chapter one, however, only 31% of Canadians diagnosed with FM have reported experiencing unmet healthcare needs (Statistics Canada, 2011). This statistic contradicts the key theme of unmet healthcare needs in the qualitative literature. Given this empirical ambiguity, one of this study's objectives was to develop an in-depth understanding of participants' unmet healthcare needs. In this dissertation, I have reported findings of participants' positive and mixed healthcare experiences, thereby providing a balanced perspective. I have also reported that many participants decided to pursue CAM services as a form of resisting the oppression experienced within the allopathic healthcare system. Moreover, in the previous chapter, I described that some participants envisioned an innovative system of healthcare that integrates both allopathic medicine and CAM.

The exclusion of gender and other systems of embodied differences.

The second potential critique of this grounded theory about compromised care is that it excludes a conceptualization of gender differences in participants' healthcare experiences. Before collecting data for this study, I expected to find gender differences both *within* and *across* men and women's healthcare experiences. This expectation was partly based on themes in the social science literature. For example, studies have found differences between men and women's experiences of the same illness, communication patterns, and help-seeking behaviors (Bury, 2005; Clarke, 2012; Driedger, Sanders, Gallois, Boyle, & Santesso, 2008; Paulson et al., 2002; Yunus, 2001).

As reported in chapter six, I found differences *within* the narratives of female participants. For example, I found variations in the ways in which women experienced their gender within patient-provider interactions. Some female participants reported that male providers assumed their FM was a manifestation of the stresses of marriage, divorce, and motherhood.

Given the existing literature, however, I was surprised that consistent differences *across* men and women's healthcare experiences were not found. As reported in chapter five, for example, male and female participants shared similar experiences of uncaring patient-provider interactions associated with a lack of adequate services, empathy, and legitimation. Male and female participants also shared similar character traits, such as recognizing the need to be assertive in the context of advocating for their healthcare needs. Furthermore, as reported in chapter six, male and female participants both described that some female providers treated them more empathetically than male providers.

Despite similarities both across and within gender, I also found differences. Within these different narratives, however, I did not have enough information to analyze whether gender was a contributing factor. For example, I found that all male participants and some female participants had experienced a mixture of positive and negative patient-provider interactions, while three female participants reported only experiencing positive interactions. Interestingly, the latter three participants were white, middle-class women who shared common traits, including articulate speech, senses of humor, and friendly demeanors. Although inferences cannot be made from a small, non-representative sample, I wonder whether participants' race, class, and likeability were protective factors that contributed to their positive experiences.

Despite the absence of overt gender differences, we cannot assume that differences between male and female participants did not covertly exist. I wonder whether the silence of gender is due to taken-for-granted norms of gender, which are embodied in our experiences of daily life (Johnson & Repta, 2012). In other words, are constructions of gender like cosmetics that we can choose to apply to our faces or have these constructions absorbed into our pores to the point of invisibility to ourselves as well as others (Butler, 1988)?

In addition to the impact of internalized gender norms, I find it difficult to distil the nuances of gender in such a small sample of men. The sample of focus groups participants included four men and 21 women. During the recruitment stage, many more women than men expressed interest in study participation, possibly reflecting diagnostic trends. Because of differences in help-seeking behaviors and doctors' diagnostic procedures, many men could have FM but be suffering in silence and without a diagnosis (Bury, 2005; Clarke, 2012; Paulson et al., 2002; Yunus, 2001). A larger sample of men is required in order to adequately

compare gender across categories of men and women. Consequently, further research is required in this area.

The Importance of Legitimacy within Patient-Provider Interactions

This study did not provide evidence to conclude whether or not the healthcare experiences of male and female participants were deeply impacted by gender differences. However, a clear finding both within and across male and female participants was that the presence/absence of the discourse of illegitimacy impacted patient-provider interactions. For example, all narratives of participants who reported uncaring interactions revealed that providers considered FM an illegitimate condition. Conversely, all narratives of participants who reported caring interactions revealed that doctors treated them with legitimacy. In fact, in these narratives of caring interactions, it appeared that providers considered it an ethical role and responsibility to believe in patients' experiences and realities. Furthermore, these narratives of caring interactions highlighted how participants' experiences of being believed by providers were therapeutic encounters that reduced "surplus suffering" (Clarke, 2014; Clarke, 2013; Clarke & van Amerom, 2007; Clarke & Fletcher, 2004). This finding about the presence/absence of legitimacy echoes themes in the existing literature; some research studies, examining patient-provider interactions, have found that providers' validation and empathetic responses were defining factors in both the quality of the patient-provider relationships and the patients' senses of well-being (May et al., 2004; Wainwright et al., 2006).

Strategies to diminish the discourse of illegitimacy.

Provider education.

The findings of this study prompt the question of how can we spread a discourse of legitimacy while diminishing the discourse of illegitimacy within the context of our current neoliberal society. How do we promote macro-level change? Can micro-level changes lead to changes in macro-level discourses? These questions were indirectly answered by participants. For example, when I asked participants about their vision for health system change, some participants argued that education could be harnessed as a tool for legitimation to improve providers' knowledge of FM and responsiveness towards patients with this condition. Similarly, within the empirical literature on patient-provider interactions, researchers suggested that providers required further training to improve their: skills for communication and patient collaboration (Driedger et al., 2008); abilities to effectively diagnose and treat FM (Briones-Vozmediano et al., 2013); and, capacities for empathetic patient interactions, as well as for addressing patients' physical and emotional needs in both an individualized and holistic manner (Haugli et al., 2004). I would add that empathy is more than a need: empathy is a human right.

In addition to improving empathetic responses, doctors require training in order to understand that FM is not an isolated condition and to effectively assess and treat comorbidities. After all, the management of multiple chronic conditions is a complex process (Taylor & Sirois, 2014, p.332). Furthermore, doctors require training on how to empathically communicate to patients the rationale behind their decisions to either provide or not provide referrals and/or further assessments. As described in chapter five, most participants reported suffering from numerous comorbid conditions. Many participants also discussed how doctors were either reluctant or refused to provide referrals and assess the existence of other conditions. Conversely, participants who experienced caring interactions explained how

doctors took responsibility for assessing comorbidities. Consequently, these findings highlight that legitimation is connected to comprehensive assessments, an essential component of ethical healthcare.

Revisiting the medical visit.

I find it interesting that in this study OHIP regulated billing practices were one of the structural barriers commonly described by participants as an impediment to legitimation. Chapter five, for example, reported that many participants explained that because they suffered from FM -- as well as other complex, chronic, and co-morbid conditions -- they required longer medical appointment times than allowed by OHIP. However, participants stated that doctors enforced the OHIP driven one-symptom-per-appointment rule, and thus numerous health concerns were unaddressed. These findings contradict the current billing regulations, as outlined in the 2014 OHIP *Schedule of Benefits for Physician Services.* This *Schedule* has an extra billing code for FM; the K037 code enables doctors to bill for longer FM patient visits and does not list a time limit for these visits (Ministry of Health and Long-Term Care, 2014). The only restriction is the visit must be booked in advance for billing tracking purposes. Furthermore, another limitation is that the *Schedule* does not have a consultation code that allows doctors to bill for initial consultations, which take an estimated 90 minutes. As a solution, however, doctors could potentially apply other billing codes; for example, there is a geriatric consultation fee code which could be adapted for older patients with FM (Dr. A Bested, personal communication, October 28, 2014).

I question why doctors' abilities to extra-bill with the OHIP K037 code contrasts with participants reported experiences of brief medical visits. Could doctors either be unaware of this billing code or unwilling to allocate additional time to patients with FM? Could doctors

be providing additional time while patients are losing track of this time due to the extensive numbers of health concerns they may wish to address during a single visit?

A plausible explanation is provided in a British study that examined family doctors' conceptualizations of chronic illnesses (May et al., 2004). The authors of this study offered two propositions to explain the relationship between the durations of appointment times and patient validation. The authors theorized, "The doctor's capacity for empathy with the patient's presentation of symptoms is associated with the doctor's perception of a successful exit point in the consultation" (May et al., 2004, p. 153). The authors' next proposition was:

> Where no exit point is in sight, and the consultation is the focus of work to *contain* the *expression* of symptoms, rather than relieve or palliate their effects, the doctor is frustrated and the doctor-patient relationship itself has the potential to become chronic (May et al., 2004, p. 153).

In view of these findings, I posit that doctors may be reluctant to extend appointment times due to perceptions/concerns about how much time and energy will be expended during the visit. Furthermore, doctors' reluctance to extend appointments could be connected to their feelings of frustration and helplessness that are triggered by their inability to cure chronic illness. In chapter five, participants shared their perspectives about how doctors' helplessness led to uncaring interactions. Regardless of the reason why doctors do not extend appointments, the result is many patients report experiences of ongoing invalidation by providers. A related issue is that doctors' potential reluctance to extend visit times could contribute to increased healthcare costs in the long-term.

When envisioning healthcare improvements, some participants articulated that the system could be simultaneously more caring and cost effective. For example, participants

argued that although prevention should be an important healthcare focus, preventative services were lacking for the FM patient population. Moreover, participants reported an increased sense of self-efficacy when providers spent time teaching them self-management skills; some of these participants reported that the teaching of self-management skills led to increased independence and reduced frequency of medical visits. These two findings highlight that if medical providers spent additional time with patients (and are financially covered by the OHIP K037 billing code), then over time these initially longer visits could potentially lead to shorter and less frequent visits, thereby reducing healthcare expenditures.

Biomedicalization reinforces illegitimacy.

I now return to the question I raised at the beginning of this section as to whether micro-level changes could help diminish the macro-level discourse of FM illegitimacy. On one hand, the findings of this study suggest that changes in patient-provider interactions, such as longer visit times, could potentially increase patients' experiences of validation and self-efficacy. On the other hand, I am skeptical about whether micro-level changes can remove the discourse of illegitimacy that is systematically saturated into aspects of our neoliberal society and the healthcare system. The reason for my skepticism is based on biomedicine's repeated attempts to biomedicalize FM, as discussed in chapter three.

The process of attempting to legitimize FM through biomedicalization is paradoxically problematic. As previously reported, some participants initially experienced relief by obtaining a diagnostic label because the diagnosis helped them to make sense of their symptoms. However, these participants eventually found that the diagnosis perpetuated illegitimacy. This illegitimacy was linked to the discourse of mind-body dualism whereby doctors assumed that FM was a psychosomatic condition because they could not find a

specific physical etiology. It can be argued that participants unintentionally internalized biomedical prejudices, assumptions, and fears about psychosomatic conditions. This prejudice was reflected in the narratives of participants who solely focused on the physical dimensions of FM in order to reduce the association between FM and psychosomatic discourses.

The discourse of mind-body dualism pushes society away from a holistic, integrated and embodied approach to healthcare. An integrated and embodied approach would recognize the inextricable connection of mind and body, thereby privileging the ways in which mental and physical health are equally legitimate, valid, and real. I agree with Einstein and Shildrick's argument that "women's health should question that boundaries are constructed (2009, p. 298). Questioning the boundaries of the mind-body divide would make room for an embodied approach to women's health, as well as for the health of people of all genders. Furthermore, an embodied approach "would necessitate the development of new models of care for long term or chronic disease…" (Einstein & Shildrick, 2009, p. 298). This embodied approach fits with participants' visions for creating a new healthcare system, as reported in chapter seven. Unfortunately, I think that as long as our neoliberal society remains preoccupied with biomedicalization the discourse of mind-body dualism will prevail, thereby continuing to constrain the development of embodied approaches to healthcare.

The need for building societal infrastructures.

Over-medicalization is one of the obsessive functions of our neoliberal society, which emphasizes healthcare needs while minimizing the contribution of other social factors (Clarke et al., 2003). We biomedicalize at our peril: the current allopathic medical model is neither capable of dealing with the complexity of FM nor has the resources to effectively

support patients living with this condition (J. N. Clarke, personal communication, October 24, 2014).

We must focus on building the infrastructure of other societal systems to help improve the quality of life for people with FM. In this study, many participants expressed this need. They reported that they required workplace modifications, reduced barriers for receiving disability pensions, and homemaking services to help them with activites of daily living.

These themes are echoed in the qualitative literature on FM about employment and self-management skills. For example, a study, which examined the employment experiences of women with FM, found that many participants wanted to work but lacked supports to help them maintain employment (Liedberg & Henriksonn, 2002). The authors advocated for the development of employment support programs, as well as for increased support from employers in providing workplace accommodations (Liedberg & Henriksonn, 2002). In comparison, in a recent study on self-management skills, the authors reported that people with FM required further supports to learn about and implement coping strategies (Kengen Traska et al., 2012). In another recent study, authors explored the experiences of people with FM who participated in a group-based exercise program and found that this program helped alleviate participants' pain while decreasing social isolation (Beltran-Carrillo, Tortosa-Martinez, Jennings, & Sanchez, 2012). Furthermore, in a study about the role of spirituality in healthcare, researchers found that people living with FM found attention to spiritual issues both helpful and healing. These researchers recommended the development of programs to address patients' spiritual needs (Offenbaecher et al., 2013).

The findings of these studies, as well as of this dissertation study, illuminate the multitude of social needs of people with FM. If the social and healthcare structures provided these supports, then the overall quality of life could potentially improve for the FM population. The problem is that in our neoliberal society, the social realm is seen as less valid than the medical realm. Neo-liberalism diminishes social supports, such as disability benefits and pensions, and offloads these responsibilities onto individuals (Ayo, 2012; Clarke, 2012). Given this fact, we must question who benefits from the biomedicalization of FM.

Who benefits from the attempted biomedicalization of FM?

Since the early 1900s, the medical model has repeatedly shifted the constructions of FM's terminology and research directions (Clauw & Crofford, 2003; Inanici & Yunus, 2004; Peterson, 2007; Powers, 1993; Wessely & Hotopf, 1999; White & Harth, 2001). Despite continued attempts to biomedicalize FM, the condition lacks credibility and biomedical prestige (Album & Westin, 2008). For example, a Scandinavian survey, which asked physicians to rank 38 diseases on a hierarchy of prestige, found that FM was ranked the lowest (Album & Westin, 2008). This study suggested that disease rankings were influenced by perceptions about a disease's etiology, acuity, lethality, and proximity to major organs.

The low prestige of FM has limited rheumatologists as benefactors of biomedicalization. What's more, a recent study described that the field of rheumatology was attempting to extricate itself from its historical designation as the medical specialty responsible for FM diagnosis and management (Ghazan-Shahi et al., 2012). Following this argument, family physicians also do not benefit from the biomedicalization of FM. The extraction of rheumatology in FM care has placed added responsibility onto family doctors.

These doctors lack resources and training to effectively diagnose, treat, and support the complex health needs of patients with FM.

The attempted framing of FM as a biomedical condition benefits the pharmaceutical companies, as they economically profit from this biomedicalization (Clarke et al, 2003). Within this system of bio-looping, the more FM is diagnosed, the more overtaxed providers will prescribe medications such as Lyrica and the more pharmaceutical advertisements will be displayed in the media. As reported in chapter five, however, participants described how doctors overprescribed medications, and how they also experienced intolerable side effects. Study participant Lori summarized the issue by explaining that advertisements for Lyrica mischaracterized FM by marketing it as "a condition characterized by widespread pain in the nerve endings."

> Well no, that's one tenth of what fibromyalgia is. Maybe one thirtieth of what it is. It's all of these other things, it's all of us having problems in our intestines, it's all of us having problems in our heads, it's all of us having these different sensitivities, multiple sensitivities to foods, to medications, to things in the environment and if you break this down to something that just says it's widespread pain in the nerve endings so that they can sell their medications, I think that *totally sucks* and it does *all* of us a huge disservice. It's just to sell meds. Now I've tried both of those meds and I can't tolerate either one but it is supposed to be the be all and end all.

Ironically, the treatments participants reported as most helpful were CAM treatments not covered under OHIP, including massage, acupuncture, and naturopathy. This finding highlights that participants who resisted the allopathic healthcare system still experienced difficulty accessing care. Moreover, this finding illuminates that inaccessible care is punitive

care. In summary, neo-liberalism creates and perpetuates inequality and cruelty: a system of compromised care.

Implications of this Study

Relevance to Social Work Principles and Values

Both my clinical social work experience and academic training have been shaped and enriched by transdisciplinary perspectives about healthcare. At the same time, I have maintained and nourished my identity as a social worker by being consistently connected to and grounded by the principles and values of the profession. This study contributes to the field of social work by reflecting the profession's commitment to social justice, equity, applied research, and transformative practices. As I described in chapter one, for example, the impetus for this study was based on my clinical practice experiences and observations that patients with FM experienced stigma within the healthcare system. I subsequently decided that this topic required empirical examination as a first step towards the goals of social justice and change. Social change is being fostered by this study because the research findings have led to a better understanding of the healthcare experiences of both men and women with FM. These findings will be shared through effective knowledge translation strategies including a community art gallery. The objectives of knowledge translation strategies are to improve the understanding of healthcare provider, decrease bias and stigma, and percolate innovative, patient-centered approaches to service delivery.

Relevance to the Delivery of Healthcare Services

Program development.

The research findings have contributed knowledge about clinical practices and methods of service delivery that could be helpful and healing to the FM patient population.

Social workers are specifically trained to: view individuals as socially located; recognize the interconnection of micro, mezzo, and macro level contexts; and, collaborate with a wide variety of stakeholders. Given this training, social workers are well positioned to both lead and assist with the development of integrated healthcare services for the FM population. These services should view patients with FM as unique individuals situated within systems of embodied differences. A potential starting point in the development of services would be for social workers to learn from existing models of chronic disease management programs, which are based on patient-centered values, transdisciplinary perspectives, and multi-faceted interventions (Taylor & Sirois, 2014, p. 332). Social workers could collaborate with managers and healthcare providers who work in these existing programs.

Clinical practice.

Social workers are trained not only to develop clinical services, but also to value and cultivate therapeutic rapport with patients. A key finding of this study was that caring patient-provider interactions were based on therapeutic alliances that fostered legitimation. Given this finding, social workers can apply their knowledge of therapeutic skills and relationship-building when developing clinically effective services and providing treatments to the FM patient population.

Methodological Relevance

The field of social work.

This dissertation is timely, as I am unaware of any other FM studies that have utilized arts-based research methods. I selected an arts-based method because it fit with both the research question and values of the social work profession. This study's methodology was informed by the social work value of actively listening to the experiences of all people,

whether they are clients, community members, or research participants. Active listening corresponds to Einstein's perspective that "in order to understand people's experiences of their bodies in context, it is critical for researchers to inquire about how participants' bodies feel" (2008, p. 95). Following Einstein's perspective, the methodology of body-map storytelling is a form of narrative, which enabled me to actively listen to and probe participants' feelings about living with FM. The process of active listening helped participants to experience a sense of connection, community, and validation. As such, the study empowered a marginalized patient population.

In addition to the method of data collection, the analysis of the verbal and visual data was guided by social work principles, values, and perspectives. For example, I analyzed the data by looking at both micro and macro-level themes related to healthcare experiences. These themes included participants' interpersonal interactions with healthcare providers, individual forms of resistance, and experiences of structural barriers.

The broader healthcare system.

This study's methodology is relevant not only to the social work profession, but also to the broader field of healthcare. For example, narratives of suffering, which were historically relegated to the margins of medicine, have recently been increasingly accepted as a valid and valuable form of communication within the healthcare system. Narratives are an important area of study because they shed light on the oppression faced by many people with chronic illness (Eccleston, Williams, & Stainton Rogers, 1997; Flores, Zelman, & Flores, 2012).

During the mid to late 1800s in European societies, narrative played a central role in patient-provider interactions (Bury, 2001). Physicians, especially those tending to upper-class

patients, would gather information about patients' histories, lifestyles, and environments. They would then use these narratives in the development of treatment regimes in order to restore the health and well-being of their patients (Bury, 2001). Unfortunately, the era of in-depth patient narratives ended with the establishment of biomedicine. Biomedicine moved the study and treatment of diseases away from the clinic -- and the holistic world of the patient -- into the expert realm of the laboratory. In these laboratories, scientists researched the biological mechanisms of disease (Bury, 2001). As a consequence, the experiential knowledge of patients was no longer seen as useful. Instead, physicians were tasked with extracting patient information solely related to the signs and symptoms of disease (Bury, 2001; Eccleston et al., 1997). They assigned low status to any information that did not relate to these signs and symptoms (Waxman, 2005). During the early to mid 1900s, patients' knowledge remained devalued, while the biomedical model grew in strength and popularity, expanding from Europe to North America (Bury, 2001).

In recent years, however, the field of medicine has renewed its interest in patients' experiential knowledge (Bury, 2001). This renewed interest can be attributed to trends in morbidity rates, as well as fiscal considerations. First, as the population ages, chronic illness is becoming more prevalent. Consequently, healthcare practitioners have become focused on illness management, rather than treatment and cure (Bury, 2001). This practice involves listening to patients' narratives about the ways in which their ailments have impacted their lives (Gerhardt, 1990). In fact, "self conception is the prerequisite of illness management and its changes may severely affect coping" (Gerhardt, 1990, p. 1154). Second, healthcare has undergone an economic crisis partly because hospital care, which specializes in technologically sophisticated interventions, is very expensive (Bury, 2001). As a solution,

community medicine, such as primary healthcare, has gained prominence as an economical form of service delivery (Bury, 2001). Primary healthcare has promoted the importance of holistic practice and client-driven care. A client-driven approach to care creates space for healthcare practitioners to listen to clients' illness narratives and to gain insight into their suffering (Bury, 2001; Gerhardt, 1990). In light of this history of medical narratives, I hope that healthcare providers will both listen to and learn from the experiences of patients with FM.

Political Relevance

In addition to the methodology, the topic of FM is politically timely and relevant. In 2014, community stakeholders and researchers publicly shared findings from a community consultation and mixed-methods study. Stakeholders included the University of Toronto's Dalla Lana School of Public Health, the Toronto Central Local Health Integration Network, the Myalgic Encephalomyelitis Association of Ontario, the Association of Ontario Health Centres, and the Environmental Health Clinic at Women's College Hospital. This study (Burstyn, 2013) examined the healthcare experiences of Ontarians living with the contested and often comorbid conditions of FM, myalgic encephalomyelitis (ME), and multiple chemical sensitivities (MCS). Based on this study's findings, stakeholders proposed a model for delivering primary healthcare services to Ontarians with FM, ME, and MCS. In this model, comprehensive healthcare services, which address the social determinants of health, would be provided by community health centres in conjunction with support and training from Women's College Hospital in Toronto. If this proposed model receives funding from the Ministry of Health and Long-Term Care, then there will be future opportunities to collaborate with academics, practitioners, and policymakers in order to conduct research, as

well as to design, implement, and evaluate healthcare programs for this population. Because of this provincial momentum, the dissertation study is both timely and politically relevant.

FM has received attention not only at the provincial but also at the federal level. In October 2014, CIHR recently announced a Fellowship competition for researchers working in the area of FM. The attention from CIHR highlights that FM is slowly creeping into public consciousness as a condition worthy of further exploration.

Future Research Directions

This study is the first phase in a program of research focused on gender and contested conditions. The findings of this study have illuminated a multitude of future directions for research. For example, a limitation of this study was that it did not explore the experiences of healthcare providers. As a consequence, the findings about healthcare providers' praxis and attitudes were solely based on participants' reporting of their healthcare experiences. Further research is required to examine providers' attitudes towards and practices for patients with FM. Studies about providers should compare the experiences of male and female providers from diverse social locations. It would also be useful to examine and compare the experiences of providers working in CAM, as well as in primary and secondary healthcare settings. The study could have an applied research component by bringing providers together to develop a transdisciplinary approach to FM care. I also suggest that a future study should compare the experiences of patients and providers, bringing both groups together in order to dialogue about what it is like to both obtain and deliver healthcare services. These studies could lead to the development of a best practice manual for healthcare providers who work with FM populations.

As previously discussed in this chapter, another important research direction is the further exploration of gender and systems of embodied differences in the context of FM. Future studies will require larger samples of men for comparative gender analyses. In addition to comparing differences across gender and professions, this study's findings raise many other interesting issues to examine in future research including:

- examining the prevalence of suicidal ideation in people with FM in order to develop best practices for suicide prevention and intervention with this population;
- how chronic conditions impact sexuality and intimacy in relationships;
- how the policies and practices of insurance companies impact people with chronic conditions who are on work leave;
- how chronic conditions impact aging populations in Canada;
- how people qualitatively experience cognitive changes as a result of FM;
- how people with FM cope with social isolation;
- how body-map storytelling could be utilized as a therapeutic intervention for people with FM.

Conclusion

Language is inadequate to articulate the visual power of participants' body maps. As such, I close this dissertation with participant Susan's representation of her identity and healthcare experiences. In my mind, Susan's body map encapsulates the themes of resilience and struggle. What do you see?

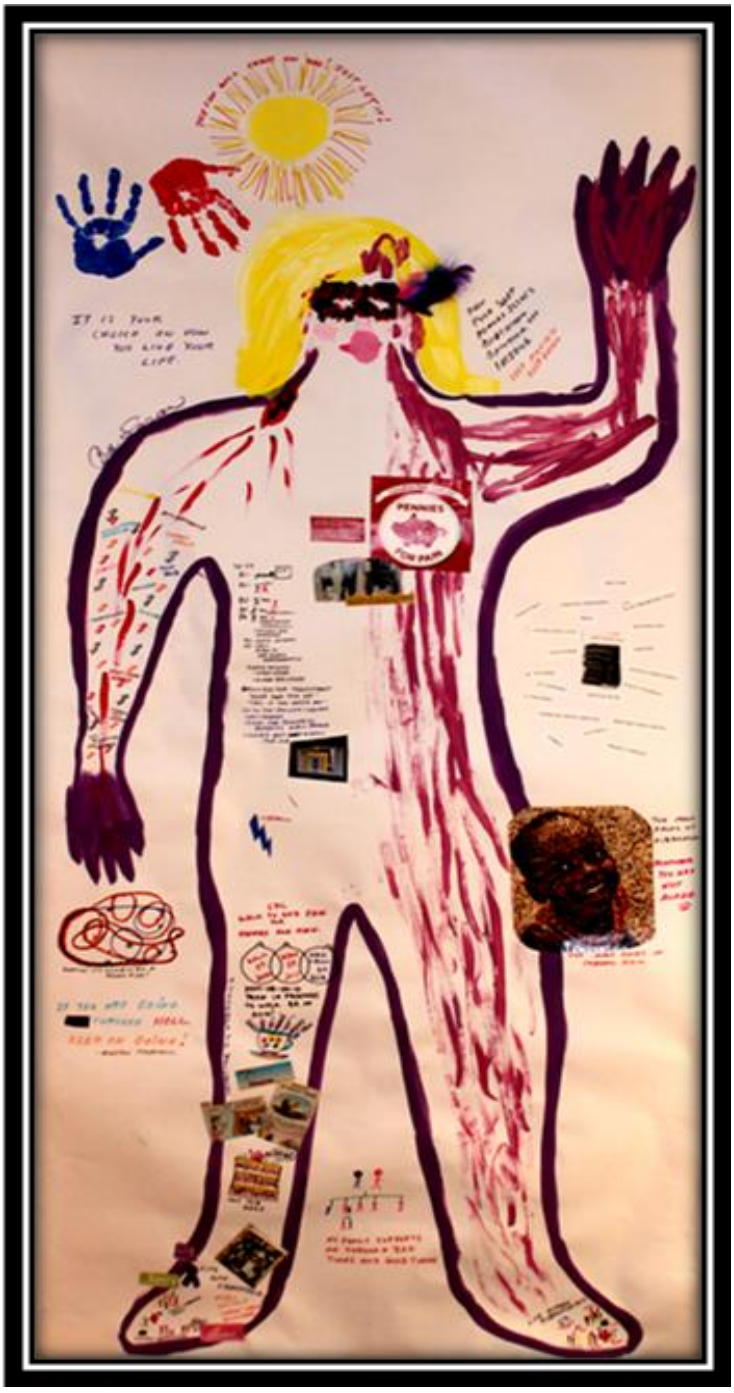


Figure 124: Susan’s body map.

Appendix A: Information Letter

Dear Potential Participant:

I, Michelle Skop-Dror, am a Registered Social Worker and PhD Candidate in the Faculty of Social Work at Wilfrid Laurier University. I am conducting a dissertation study entitled **Maps of Marginalization: Exploring the Healthcare Experiences of Men and Women with Fibromyalgia**. The purpose of this research is to explore men and women's healthcare experiences as patients seeking diagnosis and treatment for fibromyalgia. This is a one year exploratory qualitative study. In the first two months of the study, I intend to facilitate focus groups located in Toronto. Each participant will be asked to participate in a total of five focus group sessions occurring every other week. Each focus group session will last about 2 hours. If you are unable to attend the focus group sessions, then we can discuss the possibility of having an in-depth individual interview located either in or near your home. The interview will last about an hour.

I am hoping you might be interested in participating in this research. I have included a copy of the consent form so that you would know the potential risks as well as benefits of participating. You must be over the age of 18 and have previously received a diagnosis of fibromyalgia.

This study has received approval from Wilfrid Laurier University's Research Ethics Board (tracking #: 3385).

If you would like to learn more and might be interested in participating, please give me a phone call or email me and ***leave me your telephone number and email address*** so I can reach you. I would be very happy to discuss the details of this research and to answer any questions you have. Because I am seeking as much variation as possible, in terms of diversity in the group, I will also be asking you a few questions about yourself in an attempt to get as diverse a group of participants as possible.

Please contact me at:
Phone: 416-388-7378
Email: skop1770@mylaurier.ca

Sincerely,

Michelle Skop-Dror, MSW, RSW

Appendix B: Screening Script

Name:

Address:

Email Address:

Telephone number:

Do you currently have a diagnosis of fibromyalgia?

When did you receive the diagnosis?

Who diagnosed you?

Do you have any other diagnoses?

Are you currently undergoing any treatments for fibromyalgia?

I am trying to recruit a diverse group of participants for the focus groups. The reason why I am interested in diversity is because diversity may impact people's healthcare experiences. For example, a person who is white may have different experiences than someone who is black. As such, would it be ok if I asked you some personal questions? Please know that you are under no obligation to answer any questions that make you uncomfortable.

Gender: Race, ethnicity: Age:

Religion: Sexual orientation: Disabilities:

Relationship Status:

Education: (How far did you go in school)?

Occupation: (If not working now, what kind of work did you do when you were able to work?

Any other variables of difference that you think are relevant to your experience as a patient in the healthcare system:

Are you available to participate in 5 focus group sessions? They will be approximately two hours in length for a total of ten hours of participation.

Would you be open to participating in an arts-based research project? This project would involve drawing your body in order to express your stories about your healthcare experiences.

Availability:

I will get back to you shortly about whether I can include you in a focus group and if so, provide details about the focus group time and how to be part of it.

Should you wish to discuss this further, feel free to contact me:

Tel: 416-388-7378

Email: skop1770@mylaurier.ca

Thank you so much for your interest.

Appendix C

WILFRID LAURIER UNIVERSITY

INFORMED CONSENT STATEMENT

Maps of Marginalization: Exploring the Healthcare Experiences of Men and Women with Fibromyalgia

ADVISORS

1. Dr. Carol Stalker, Professor, Faculty of Social Work, Wilfrid Laurier University
   Email: cstalker@wlu.ca Tel: 519-884-0710 ext. 5217

2. Dr. Juanne Clarke, Professor, Sociology Department, Wilfrid Laurier University
   Email: jclarke@wlu.ca Tel: 519-884-0710 ext. 3516

DISSERTATION COMMITTEE MEMBERS

3. Dr. Marshall Fine, Professor, Faculty of Social Work, Wilfrid Laurier University
   Email: mfine@wlu.ca Tel: 519-884-0710 ext. 5223

4. Dr. Gillian Einstein, Professor, Department of Psychology, University of Toronto
   Email: gillian.einstein@utoronto.ca Tel: 416-978-0896

You are invited to participate in a research study. The purpose of this study is to explore the healthcare experiences of men and women who have a diagnosis of fibromyalgia. Participants should be men and women over the age of 18 who have been previously diagnosed by a physician with fibromyalgia.

The researcher, Michelle Skop, is both a Registered Social Worker and a PhD Candidate in the Faculty of Social Work at Wilfrid Laurier University.

INFORMATION

This study's central question is: How do men and women who have a diagnosis of FM experience interactions with health care providers? This question will be answered through a series of individual interviews, focus group sessions and an arts-based research project.

Interviews: Individual interviews will be conducted in cases where participants are unable to attend the focus group sessions. Each interview will take approximately one hour and will be conducted in a location agreed upon by both participant and researcher.

Focus groups: Each focus group will meet for five sessions every two weeks. In session one, participants will be asked to share and discuss their healthcare experiences.

In sessions two to four, participants will be asked to participate in an arts-based research project. This particular project is called body-map storytelling, an adaptation of body mapping for research purposes. Originating in South Africa, body mapping is a form of storytelling, which enables participants to explore their experience of illness, as well as their life journeys, through life size self portraits. The benefit of body maps is that art enables people to express thoughts, ideas, and feelings that may not be easily expressed through verbal communication. The body maps will be used as a research tool for participants to narrate their journeys through the healthcare system. Participants will first work together with a partner; they will take turns tracing their bodies on full size paper. This activity does not involve physical touch, but will place people in close proximity with each other for a short period of time (around 15 to 20 minutes). Participants will then resume individual work by filling in their body outlines with words, images, and drawings related to their identity as a person living with fibromyalgia.

In session five, participants will be asked to take turns sharing their body maps with the rest of the group. This process involves the participant describing the body map to the group (e.g. the meaning of imagery, words, and symbols). This is not meant to be an intrusive process, and therefore participants can share either as much or as little information as they feel comfortable doing.

After the completion of the five focus group sessions, a community forum in the form of an art gallery will be organized to showcase the body maps. The objective of the community arts gallery is to share participants' visual narratives about their experiences in the healthcare system, thereby raising awareness and decreasing stigma about fibromyalgia.

Each of the five focus group sessions will be two hours in length for a total of ten hours of participation for the duration of the study.

A research assistant will attend the focus group sessions in order to assist with note taking and to help participants draw their body maps if required. This assistant will be a Master of Social Work student from the Faculty of Social Work at Wilfrid Laurier University or an undergraduate student in the Department of Psychology at the University of Toronto.

A total of 42 participants will participate in this research study. There will be five focus groups. The first group will be involved in a pilot study. This pilot study will include one group of six to eight people. The following four groups will include both men and women as long as all participants agree. In the event that some participants prefer a single gendered group I will have a focus group for women only and possibly another one for men only (if there are sufficient numbers).

There will be an opportunity for ten individual interviews with participants who are unable to attend the focus groups.

As part of the selection process for this study, I will screen potential participants via phone in order to confirm a diagnosis of fibromyalgia and availability to participate in multiple focus group sessions. I will also ask personal questions about demographics because I am trying to recruit a diverse group of participants for the focus groups. The reason why I am interested in diversity is because diversity may impact people's healthcare experiences. For example, a person who is white may have different experiences than someone who is black.

I request your permission to audio record each individual interview and focus group session in order to ensure that participants' words are captured accurately. This material will be strictly used only for the purpose of the research. Only a hired transcriber and I will have access to the audio tape, which will be kept on a password protected audio recorder, as well as in a password protected computer file. The transcriber, who will transcribe the audio tape, will keep all information confidential. The transcripts will be kept in password protected computer files, which only I have access to. The transcript will be used to analyze the research data. I will keep the audio recordings and transcripts for a period of seven years in order to use the data for further analysis and the writing of journal articles. After seven years, I will dispose of the data by erasing the audio recordings and deleting the transcripts from the computer. The audio tapes will not be used for any additional purposes without your additional permission. If you withdraw from the study, you have the right to request that your information not be used in the analysis of the data. You also have the right to request to listen to the audio tape at any point during the study.

I request your permission to keep your body maps until the community art gallery, which will be held in the winter of 2014. The body maps will be stored in a secure location. Before returning your artwork, I will take photographs of your body maps for the purpose of data analysis and dissemination of the research findings.

There is no deception or concealment in this study.

RISKS

If participants choose to complete the body maps (e.g. drawing and painting) while seated on the floor, they may be at risk of straining their knees and backs. This risk will be minimized by having frequent stretch breaks, as well as avoiding floor work by having large table surfaces and wall space to work on.

Body maps can be an emotional process because they promote people to reflect upon their experiences, both positive and negative. For example, it is possible that participants may feel emotionally triggered (e.g. thinking about past negative healthcare experiences) during the focus groups and body map exercises. In order to minimize this risk, at the end of this document, there is a list of crisis lines and available counseling services. Furthermore, in order to provide direct support, I will circulate around the room during the body map exercises, encouraging participants and engaging in conversations about their work.

Those participants who participate in the study through an individual interview may also feel emotionally triggered (e.g. thinking about past negative healthcare experiences). In order to

minimize this risk, I will distribute a list of crisis lines and available counseling services to these individuals.

BENEFITS

The research benefits this researcher because it will shed light on a topic, which became a concern through my clinical practice. During my experience working as a social work coordinator in a home healthcare organization, I observed that people with fibromyalgia experienced discrimination by healthcare professionals because their illness was considered contested and controversial. This study will help me to develop a deeper understanding about these experiences of discrimination and to foster social change through knowledge translation.

The research may benefit participants by providing opportunities for them to vocalize their stories of oppression within the healthcare system. These stories may have been silenced in the past. Arts-based research methodologies, such as body maps, enable people to holistically communicate both their verbal and non-verbal experiences. Therefore, participation in the research could lead to a sense of empowerment, affirmation, and increased self esteem. Furthermore, the literature reports that many people with fibromyalgia are socially isolated. Given this fact, participation in focus groups may lead to reduced isolation, an increased sense of belonging, and opportunities to broaden one's social network.

The research may benefit the research community and society at large because the study's findings will be disseminated through a community arts gallery, conferences, and presentations. These forums for knowledge translation will help inform health researchers, practitioners, and policy makers about the stigma people with fibromyalgia encounter in the healthcare system. This information may then lead to increased understanding about the experiences of living with fibromyalgia, thereby decreasing bias and discrimination.

CONFIDENTIALITY

To protect identity and privacy, participants' information (e.g. screening notes, field notes, consent forms, etc.) will be kept in a locked filing cabinet, as well as in password protected computer files, which only I have access to. The body maps will be stored in a secure room. Furthermore, the focus group sessions will be held in a private room.

One issue that comes up in focus groups is the fact that confidentiality cannot be guaranteed because all those present at the focus group hear what everyone else says. As a remedy, participants will sign a confidentiality agreement pledging to not share any personal information emerging from the focus group sessions outside of the groups.

To maintain anonymity, participants will not use their own names. Instead, they will select pseudonyms, which will be connected to their quotes and body map pictures in the research findings. Furthermore, other identifying information that is too revealing (e.g. name of healthcare provider, age, place of residence) will be changed to protect participants' identities.

The research findings will be published on a study website, in a dissertation report, journal articles and books, as well as distributed to healthcare providers. You quotations and body maps will be used in manuscripts and presentations and displayed on a study website, but these quotations and body maps will omit any identifiable information.

Participants' information, quotations, and artwork will only be included on the study website and in the art gallery, final report, publications, and presentations with their signed consent.

COMPENSATION

Focus groups: For participating in this study you will receive bus tokens to travel to and from all of the group sessions, as well as $100 divided into two installments of $50. One installment will be given during the first group session and the second installment will be given during the last group session. If you withdraw from the study prior to its completion, you will receive only $50.

Individual interviews: For participating in this study you will receive $20.

CONTACT

If you have questions at any time about the study or the procedures (or you experience adverse effects as a result of participating in this study) you may contact the researcher, Michelle Skop, at the Faculty of Social Work, Wilfrid Laurier University, 120 Duke Street West, Kitchener ON, N2H 3W8, (416) 388-7378 or skop1770@mylaurier.ca. This project has been reviewed and approved by the University Research Ethics Board (tracking number: 3385). If you feel you have not been treated according to the descriptions in this form, or your rights as a participant in research have been violated during the course of this project, you may contact Dr. Robert Basso, Chair, University Research Ethics Board, Wilfrid Laurier University, (519) 884-1970, extension 5225 or rbasso@wlu.ca

PARTICIPATION

Your participation in this study is voluntary; you may decline to participate without penalty. If you decide to participate, you may withdraw from the study at any time without penalty and without loss of benefits to which you are otherwise entitled. If you withdraw from the study, every attempt will be made to remove your data from the study, and have it destroyed. You have the right to omit any question(s)/procedure(s) you choose.

FEEDBACK AND PUBLICATION

The results of the research will be disseminated in a dissertation, books, journal articles, and conference presentations, as well as on a project website. Furthermore, the body maps will be displayed at a community art gallery at the end of the study. Upon request, participants will be provided with an executive summary of the research findings at the conclusion of the study.

CONSENT

1. I have read and understand the above information. I have received a copy of this form. I agree to participate in this study.

Participant's name:_____

Participant's signature_____ Date _____

Investigator's signature _____Date _____

2. I provide permission for my quotations and body maps to be used in the final research report, as well as on a study website and in publications and presentations about this research. I also provide permission for the body maps to be displayed at a community art gallery at the end of the study. I am aware that my identity will be concealed and will not be linked to my quotations and body maps in order to protect my privacy and confidentiality.

Yes_____ No_____

Participant's signature_____ Date _____

Investigator's signature _____Date _____

Appendix D:

Interview Guide for Individual Interviews and First Focus Group Session

1) Why were you interested in participating in this study?
2) What was your life like before you were diagnosed with FM?
3) How did you find out that you had FM?
4) How does the diagnosis of FM affect your life?
5) What does a positive interaction with a healthcare provider look like? (Please describe this encounter from the moment you walked into the waiting room).
6) What does a negative interaction with a healthcare provider look like? (Please describe this encounter from the moment you walked into the waiting room).
7) How do interactions with healthcare providers impact your relationships with families, friends, and work colleagues?
8) What are your suggestions for improving healthcare services for people with FM?

Appendix E: Confidentiality Agreement

Maps of Marginalization: Exploring the Healthcare Experiences of Men and Women with Fibromyalgia

In order to protect focus group members' confidentiality, I agree to not disclose any information shared in the focus group sessions outside of the focus groups.

Participant's name:_____

Participant's signature_____ Date _____

Investigator's signature _____Date _____

Appendix F: Focus Group Safety Rules

Example from Mid-Toronto Focus Group – March 6, 2013

The following rules were generated by focus group members to ensure that the group environment feels emotionally and physically safe:

It is already helpful that:

- Protocols are in place to ensure confidentiality of material
- We have informed consent forms

We will:

- Pause the conversation if someone from the church enters the room
- Not have any cross talk
- Not interrupt others
- "Agree to disagree" (e.g. no personal attacks)
- Respect and honor all members' views
- Not dominate the group and silence others
- Have equal time to talk
- Check in at the beginning of each focus group session and debrief at the end
- Inform the group of any food allergies
- Stand, stretch and move around the room as often as needed
- Be very careful when touching others to prevent pain

Michelle will:

- Speak to church administrator to reduce the risk of people entering room

- Facilitate the group to ensure we stay on topic and keep within the 2 hour time limit

Emotional triggers:

- We will process issues as they arise on a case by case basis
- If a group member is emotionally triggered and needs to leave the room, she will inform the group: “I need to step out for a bit”
- Michelle will check on the group member who has left the room

Appendix G: Body-Map Storytelling Art Tips and Exercises

- ***Remember that there is no right or wrong!!!***
- ***Enjoy the process!!!***
- ***Celebrate your authenticity***

- You can write notes to clarify your thoughts and remember what you want to draw
- Please develop a key on the lined paper to explain what your symbols mean (e.g. bird = hope, black paint = despair, jagged lined = pain)
- You can trace your body in unique positions (e.g. sideways profile, face front, arms extended in air, arms down, etc.)
- In comparison to colors, shapes and lines can depict emotions:
    - A jagged line can express pain or excitement
    - A smooth line can express calm or feeling flat
    - A diagonal line can be dynamic
    - A broken line can express frustrations or being stopped
    - A curvy line can represent process
- Feel free to add words, poetry, photographs, images
- Words can...
    - Be written around or inside your body map
    - Be written inside shapes
    - Follow the curves of your map
    - Form shapes

- You can fill in the negative space (i.e. the space outside of your body)
- You can overlap images
- Layers of tissue paper can represent the layers of your soul
- You can add a layer of paint, let it dry, and then draw/write with markers on top
- You can write words with a wax candle and then layer paint on top
- Adding water will thin the paint
- Adjusting the hue:
    - Add white to turn the paint lighter
    - Add black or a darker color to darken the paint
- You can mix the paint to make new colors
    - Red and yellow = orange
    - Blue and yellow = green
    - Red and blue = purple
- Please stop painting at 12:30 to ensure that the paint has time to dry by the end of the group
- Please remember to wash your brushes at the end of the group

Body Mapping: Session 1

Our Health and Illness Biographies

- The following manual has been adapted from:

Gastaldo, D., Magalhães, L., Carrasco, C., and Davy, C. (2012). Body-map storytelling as research: Methodological considerations for telling the stories of undocumented workers through body mapping. Retrieved from http://www.migrationhealth.ca/undocumented-workers-ontario/body-mapping

- Last week, we talked about some of our healthcare experiences. Today we will begin to visually explore these experiences through the creation of body maps.

Activities:

Body Tracing

a) Think about a position or a posture that best represents who you are and how you feel about your current health
b) Trace your body with the help of a partner
c) Pick a colour that best represents you
d) Highlight your body shape with paint or a marker
e) Pick a colour that represents your hands
f) Outline your hand on the map or put on a glove, cover the glove with paint, and imprint it on the map

Self-Portrait

a) How would you like to represent your face?

- As it appears or in a more symbolic way?

Illness Biography

a) What did your life look like before you developed FM?

b) What does your life and health look like now?

c) If you look from head to toe on your body map, can you identify any specific marks on your body that are related to FM?

- What does FM look like?
- Where is the pain? What are the symptoms?

Homework Activity

a) In the next session, we will draw our journeys of being diagnosed and treated within the healthcare system. In preparation, please draw a symbol that represents your healthcare journey.

b) Think about where this symbol should be placed on your body (e.g. on top of your head, in your chest, on your leg, etc).

c) You will be asked about the meaning of the symbol and its location on your body map.

d) Create a personal slogan (e.g. a statement, a saying, a poem, a song, a prayer, something you say for yourself) that describes your philosophy about your health or your current thinking about your health.

e) Think about where to place the personal slogan on your paper.

f) Feel free to bring magazine pictures or mementos that you would like to paste onto your body map.

Body Mapping: Session 2

Our Healthcare Journeys

Today we will draw our journeys through the healthcare system.

Personal Symbol and Slogan

- Draw the personal symbol and slogan you have chosen to describe your healthcare experiences.

Diagnostic Journey

- I want you to think about your journey of being diagnosed with FM.

  Food for thought:

  - Which symbols or images represent this journey?
  - How did you find out you had FM?

Care

- How do you look after yourself?

  Food for thought:

  - Do you use medical or holistic interventions, write poetry, exercise, etc?
  - What is the role of your healthcare providers in your treatment?

Healthcare Interactions

- In this exercise, I would like you to think about how to represent your illness and your relationship with healthcare providers, and how these things impact your body and your well-being.

- How do you want to represent the kind of relationship you have with your healthcare providers?

  Food for thought:

  - What does a positive experience with a healthcare provider look like?
  - What does a negative experience with a healthcare provider look like?

  1. How did the best experience with a health care provider make you feel?
  2. How did the worst experience with a healthcare provider make you feel?

Homework Activity

- In the next session, we will draw our experiences of coping with the healthcare system and what makes us resilient. In preparation, please write a message to the general public regarding your healthcare experiences.

Body Mapping: Session 3
Resilience and Coping

Today we will draw our experiences of resilience/coping with FM and the healthcare system.

Message to Others:

Given all that we have explored in these three focus group sessions regarding your healthcare journey, I would like you to think about your experience as a healthcare consumer with FM.

- What message would you like to give to the public about your experiences in the healthcare system?

  Food for thought:

  - Why is it important for the public to know this?
  - Where on the body map do you want to put your message?

Body Scanning:

In this exercise, I want you to explore all aspects of your healthcare experiences. This includes issues related to gender, race, social relations and your use of services.

- Have you ever faced challenges in your interactions with healthcare providers?

  Food for thought:

  - What kind of difficulties/challenges were these?

- Now I want you to think about your strength and courage when facing these problems.

  Food for thought:

  - Where does your strength come from?
  - Where do you get the courage to keep moving forward?

- Scan your body map and focus on finding where this personal strength comes from.

  Food for thought:

- Does it come from your arms?
- Your mind?
- Is it related to your personal slogan?

Support Structures:

In this exercise, I would like you to identify key people, groups or things in your life that support you or help you cope with some of the challenges you face in the healthcare system.

Food for thought:

- Who gives you support? (It can be an organization, a person, a pet, your spirituality).
- How do these people show their support?
- What does this support mean to you?

Drawing the Future:

Finally, I would like you to think about your future.

Food for thought:

- How do you imagine your future?
- What is your vision, your goal or your dream?
- What are you working towards? (It may be something material, physical, emotional or spiritual).

Homework Activity:

In the next session, we will finish our maps and present them to the group. In preparation, please think about what you want to tell the group about your body map.

Food for thought: What is the story behind your map?

Body Mapping: Session 4

Sharing Our Body Map Stories

Today we will finish our maps and present them to the group.

Finishing Touches:

Your body map is almost ready. This is your last opportunity to add any symbols or connections that you feel are important to include for your story as a healthcare consumer living with FM.

- Is there anything missing?
- Is there anything you would like me to add or change for you?

Personal Narrative:

I would like you to take a few minutes to look at your body map and think about what it says.

- In a few words, please tell the group your healthcare journey through your body map and how you would like to be remembered by others.
- What should people know when they see your body map?

Review of Group Process:

- What worked?
- What are your suggestions for improving the future focus groups?

Although our focus group sessions have come to an end, I hope to see all of you at our community art gallery, which will be held next fall/winter.

Thank you for participating in this study!!!

Appendix H: Field Note Template for Interviews and Focus Groups

Date:

Interview/Focus Group #:

Participant pseudonyms:

- For interviews: Anything significant about the conditions/location/ setting/circumstances of the interview
- Rapport or lack of it
- Main issues or themes
- Questions to consider for the next session
- Important information shared before/after the recorder was on
- Reflexive commentary on my role and impact on the interview/group session and the impact that the interview/group session/participant had on me
- Anything puzzling, strange, unexpected, important, interesting, illuminating
- Other observations/ insights

Appendix I: List of Healthcare-Related Codes

Body Maps - Conceptual Content

- Difference
    - Age
    - Class
    - Gender
    - Geography
    - Marital Status
    - Race
- Healthcare Experiences
    - Negative
    - Positive
- Healthcare Journey
    - Maze
    - Road
    - Roller Coaster
    - Spiral
- Self
    - Pre-illness
    - Now
    - Vision for Future
- Support Systems

Body Maps - Elements of Design

- Color
- Form
- Line
- Space
- Shape
- Texture

Body Maps - Tone

- Emotion
    - Words
    - Images
        - Mobilized
        - Immobilized
        - Silenced – Mask
        - Silenced - Blank Face
    - Tears

Caring Patient-Provider Interactions

- Patient Qualities
    - Demographics
    - Expressed Gratitude
    - Positive Attitude
- Provider Qualities
    - Believing Patient
    - Collaboration
    - Containment
    - Empathy
    - Inquiring Stance
    - Taking Time
    - Teaching Coping Skills
    - Therapeutic Alliance

Compromised Care - Patient-Provider Interactions

- Discourses
    - Illegitimacy
    - Mind-Body Dualism
    - Objective Proof
- Withholding
    - Appointment
    - Assessment and Diagnosis
    - Empathy
    - Legitimacy
    - Services
- Emotional Impact
    - Trauma
        - Emotional Pain
        - Physical Pain
        - Self-Doubt
        - Suicidal thoughts

Compromised Cared - Structural Barriers

- Billing Practices
- No “Clear Path”
- No Continuity of Care
    - Loss of Consistent Providers
    - Loss of Rheumatology
    - Visiting Multiple Providers
    - Wait Times

Constructions of FM – Participant

- Chronic
- Cognition
- Depression and Anxiety
- Fatigue
- Loss
- No Relief
- Pain

Differences

- Providers
    - Gender
- Patients
    - Age
    - Class
    - Culture
    - Education
    - Family Structure
    - Gender
    - Geography
    - Marital Status
    - Migration
    - Race
    - Trauma

Focus Group Dynamics

- Communication
    - "Braided Time"
    - Cognition
    - Cross Talk
    - Dominating the Discussion
    - Isolation
    - Need to Talk
    - Not Alone
    - Sharing Information
    - Tangential
- Facilitation
    - Participants Expressed

        - Anxiety
        - Hierarchy of Experiences
        - Therapeutic Benefits

Healthcare Journey – Time Continuum

- Pre-Illness
- Illness Onset
- Interactions
    - CAM
    - PHC
    - Secondary Healthcare
    - Tertiary Care
- Seeking Diagnosis
- Seeking Treatment

Resistance

- Coping
    - Personal Growth
    - Sense of Humor
    - Trusting Self
- Self Management
    - Education
    - Seeking Alternative Treatments
    - Self-Advocacy
    - Self-Care
    - Self-Efficacy
        - Embodiments
    - Spirituality
        - Nature
        - Religion

Socio-medical Collision

- Employment
    - Have to work
    - Loss of work
    - Modified work
    - Wish to Work
- Support Systems
    - Family
        - Supportive

        - Not being believed
        - Marriage Breakdown
        - Loss of Intimacy
    - Friends
        - Changing Relationships
        - Disbelief
        - Giving Advice
- Financial Struggles
    - Insurance Companies
        - Legal Battles
        - Criminalized
        - Surveillance

Suggestions for Improvement

- Accessibility
    - Accepting New Patients
    - Cost
    - Geography
    - Wait times
    - Longer Appointment times
- Accountability
- Believe in FM
- Change Billing Practices
- Education for Providers
- Integration
    - Healthcare teams
    - Holistic Practices
    - Single Location
- Prevention
- Teaching Coping Skills

Trauma

- Pre-Illness
    - Childhood
    - Familial
    - Illness Triggers
        - MVA
        - Stress

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